



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

Health Information  
and Standards

# Best Practice Review of the Implementation of Summary Care Records

August 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 and Youth Affairs, HIQA has responsibility for the following:

- **Setting standards for health and social 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. It is therefore imperative that information is managed in the most effective way possible in order to ensure a high-quality and safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests — if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst, not given.

In addition, health information has a key role to play in healthcare planning decisions — where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision. Under section 8(1)(j), HIQA is charged with; evaluating the quality of the information available on health and social care and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available. Information and communications technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented with major gaps and silos of information which prevents the safe, effective, transfer of information. This results in the people who use the service being asked to provide the same information on multiple occasions.

In Ireland, information can be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base our decisions. As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice. A robust health information environment will allow all stakeholders: the general public, patients and service users, health professionals and policy makers to make choices or decisions based on the best available information. This is a fundamental requirement for a high reliability healthcare system.

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

Following its research into summary care records and the publication of information requirements for a national electronic patient summary, HIQA has undertaken an international best practice review of patient summary implementations, with a view to making Recommendations to the Minister for Health in respect of an Irish implementation.

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## Executive Summary

This section summarises the main findings of this review, starting with the definitions of key terms used. A patient summary is a summary of the main parts of an electronic health record that will be most useful to a healthcare professional treating a patient without access to the patient's records (for example, on holiday, visiting friends or on a business trip).<sup>(1)</sup> A shared (care) record enables healthcare providers in different settings—for example, primary care and hospitals—to view patient records with the patient's consent, or their representative's where appropriate.<sup>(1)</sup> It brings together information from various systems into a single place for care professionals to use to support the delivery of care. The ultimate goal of the Irish National EHR programme is a complete digital record of a patient's journey, from cradle to grave, across all health and social care settings.<sup>(1,2)</sup>

### England

The overall aim of the English summary care record programme was to create a national electronic summary care record for every English citizen of the population of 51 million, as part of the larger National Programme for Information Technology programme.<sup>(3)</sup> The implementation was a top-down model, which is considered to be problematic in itself—though any implementation on such a scale would have inherent challenges.

Each fully-registered active National Health Service (NHS) patient is eligible for a summary care record. A national demographics database and messaging service, known as the Spine, was established as an essential prerequisite, together with a new network and new electronic prescribing service. Pilot projects took place in two localities in 2007, while the national rollout began in 2009.<sup>(3)</sup> The clinical content of the English summary care record is automatically updated in real time, when the core data items in the general practitioner (GP) record are updated. By 2014, the summary care record programme was well-established and an Additional Information capability was introduced, which was considered especially useful for frail and elderly patients.

The programme encountered a number of early challenges and initial rollout was slow, but adoption increased as these challenges were resolved—for example, following the resolution

of challenges with the consent model, adoption rose from 50% to 80%.<sup>(4)</sup> Some of the lessons learned included ensuring that at least 50% of citizens had summary care records, otherwise healthcare professionals tended to abandon use of the system, and ensuring that it is clear if a patient has opted out of the records.

## Norway

By the early 2000s, many Norwegian hospitals and all GPs could share discharge summaries and eReferrals, but not electronic medical record data—in emergency situations, there was no patient history. The Norwegian summary care record addresses this deficit, providing a summary of the citizen's core health information, which could affect treatment administered, particularly in emergency situations. A summary care record is created automatically for all 5.3 million citizens, with approximately 5000 citizens (0.1% of the population) opting out. The Norwegian summary care record programme can be considered as a 'middle out' implementation, where Government, industry, and clinicians collaborated to create national standards for interoperability and to encourage compliance.<sup>(5)</sup> Following pilots in each of the four Regional Health Authorities, the Record was rolled out nationally in 2016. The summary care record is largely populated with information from a number of national registries and information sources—the Medications section is populated from the national 'Prescription Intermediary' system. The Critical Information section, which is updated manually, addresses the unscheduled care use case. Citizens' awareness of their data sharing options was considered crucial for the success of the programme. The summary care record was awarded a privacy award by the National Data Protection Commissioner due to all the choices that were made available to patients regarding their summary care record. The Norwegian summary care record was particularly helpful for unconscious patient, for those on multiple medications, and for patients with a history of substance abuse—reflecting a finding from a study on the Scottish emergency care summary.<sup>(6)</sup> Doctors were found to trust the automatically-updated medications list far more than the manually-updated information.<sup>(6)</sup> Programme leadership also recommended tight integration of systems, as the Norwegian doctors had to enter security credentials twice, which caused issues.<sup>(7)</sup>



## Scotland

The Scottish emergency care summary programme was a clinically-led programme to introduce a basic national summary care record, with the emphasis on maximum reuse of the existing infrastructure.<sup>(3,8,9)</sup> The first year of the emergency care summary programme was dedicated entirely to building consensus within clinical groups and to building public support.<sup>(3)</sup> Prior to implementation, all Scottish GP practices already used a standard configuration, with relatively well structured data, and the Community Health Index, a population register (database) used for healthcare purposes, was also in place.<sup>(3,10)</sup> Following a pilot in 2004, the emergency care summary was rolled out nationally in 2006.<sup>(3)</sup> Existing electronic links with GP practices were used to connect to the new national data store, built specifically to store the records.<sup>(3)</sup> Patients' medical and demographic details were, and continue to be, uploaded twice daily from GP records to the store. Separate legislation was not needed for the Scottish emergency care summary.<sup>(11)</sup> By 2011, over 99.9% of Scotland's 5 million citizens had an emergency care summary, the first summary care record programme to achieve national coverage.<sup>(8)</sup> By 2012, clinicians working in emergency situations regard the emergency care summary as a key data source, particularly for medicines reconciliation on admission to hospital. 34% of NHS 24 clinicians (Scotland's telehealth organisation) surveyed said that it had changed a clinical decision.<sup>(9)</sup>

## Northern Ireland

The Northern Ireland emergency care summary was introduced in 2010 to address the unscheduled care use case for its 1.5 million citizens.<sup>(3)</sup> The implementation was based on the successful Scottish implementation. GP practice data is uploaded to the emergency care summary, changes are then uploaded nightly. Full coverage was achieved in 2013. The Northern Ireland emergency care summary programme can be considered a 'middle-out' implementation, where Government, industry, and clinicians collaborate to create national standards for interoperability and to encourage compliance—the Project Board has representation from general practice, the Department of Health, the IT community, directors of some healthcare trusts, and the Health and Social Care Board.<sup>(12)</sup> Stakeholder engagement was considered to be a key workstream and prerequisite, including many face-to-face meetings with patients and focus groups.<sup>(12)</sup> Programme leadership was committed to use the data only for the stated purpose, which gained public confidence in the record. The quality of emergency care summary data is monitored closely, with the emergency care

summary team checking daily whether uploads from practices have failed. For example, if the GP practice has not kept pace with changes or if a practice has stopped submitting records, the record may need to be rebuilt.

## Other countries

### Estonia

Estonia has a well-established framework for all Government eServices, with Estonian e-health services using the national infrastructure and the national identifier for each citizen.<sup>(13)</sup> All healthcare providers are legally obliged to supply documents to the Estonian National Health Information System (ENHIS), which were established in 2008.<sup>(13)</sup> Key clinical information from the database is made available through the Time Critical Data, to support healthcare professionals treating patients during episodes of unscheduled care.<sup>(13)</sup> An electronic prescribing service, a national patient portal, and other key eHealth systems were established subsequently, facilitating the introduction of the Time Critical Data service. In every sector, the citizen is considered to be the owner of the data and always has the right to see who has viewed their data.<sup>(13)</sup> Patients can view all of their data stored on the ENHIS on the patient platform 'My E-Health'.

### Spain

The Spanish health system is devolved into 17 Autonomous Regions, with the State Ministry for Health mainly responsible for coordinating between these Regions and for generating a unique health identifier for each Spanish citizen.<sup>(14)</sup> Each Region assigns a specific identifier to the resident, to support regional interoperability—by 2009, 98% of Andalusian residents had a Numero Unico de Historia de Salud in Andalusia (NUHSA).<sup>(15)</sup> Other national standards have also been defined to support interoperability—for example, the minimum content for the clinical history to be used in all regional health systems, which corresponds to the patient summary use case. The Andalusian Health Service has implemented a full electronic health record system, DIRAYA, for its population of approximately 8 million citizens, using existing infrastructure and developing new components as required.<sup>(15,16)</sup> The first step was developing the Citizen Register.<sup>(15)</sup> A patient's registered GP has automatic access to DIRAYA, as do other GPs who have the patient's consent, and the emergency services. The landing page of DIRAYA shows the clinical history defined in the National Standard—that is, the patient summary. Initially, DIRAYA performance was slow, but when the technical problems were solved, many healthcare professionals appreciated it. Their suggestions for

improvement also showed a 'sophisticated understanding of health informatics and ICT possibilities'.

### **Austria**

The Elektronische Gesundheitsakte (ELGA, the Austrian 'electronic health record') is a document-sharing platform that currently supports discharge summaries, laboratory results, radiology results, and electronic referrals (eReferrals).<sup>(17)</sup> Faced with a multitude of documents, a GP may not find pertinent information—but is still held responsible for any treatment administered.<sup>(17)</sup> To address this issue, the patient summary is under consideration but has not yet been implemented in Austria.<sup>(17)</sup> A central patient register, providing demographic information, was 99% complete at the start of the Austrian electronic health record rollout.<sup>(17)</sup> Within the register, the central citizen identifier is hidden, and linked to the respective identifiers for specific areas, including healthcare and finance.<sup>(17)</sup> To access a patient's Austrian electronic health record, authentication using the patient's health card is required, and every access is monitored and stored.<sup>(17)</sup> Physicians then have access to a patient's record for 28 days after authentication—unless the physician downloads the document locally.<sup>(17)</sup> Patients may limit or extend the time that the physician can access their record.<sup>(17)</sup> Programme leadership emphasised the usefulness of structured data in GP systems, and compliance with national standards, as providing a rich source of data for an automatically-generated patient summary document.

### **Denmark**

A national patient summary has not yet been implemented in Denmark.<sup>(18)</sup> The Danish standards development organization, Medcom, has investigated the possibility of generating a national electronic patient summary, to meet the requirements of the EU cross-border project, Open National Contact Point (OpenNCP).<sup>(18)</sup> Medcom has defined national standards for discharge summaries, notifications and care reporting and considers that, together, these documents would provide the information necessary to generate a Danish patient summary that complies with OpenNCP specifications.<sup>(18)</sup> The considerations for generating a patient summary were also emphasised. When the GP generates and maintains the patient summary manually, this can create extra workload for GPs.<sup>(13)</sup> Where the patient summary is generated automatically as a persistent document from different sources, lags in updates which could cause delays. For example, a discharge summary might not be considered final, and therefore might not be sent to the patient's GP, until the final blood test results were

received, several days after discharge.<sup>(13)</sup> Finally, dynamic generation of the patient summary from different sources, often based on a central national repository, is the most technically complex and challenging approach of the three options—but also the most effective.<sup>(13)</sup> Thus, the emphasis is moving away from implementing a manually generated Patient Summary document to investigation of the possibility of generating documents ‘on the fly’ from a national central database of clinical information.<sup>(18)</sup>

## Finland

Originally scheduled for launch in 2020, the Finnish Patient Summary will be live once upgrade work on the National Patient Data Repository have been completed. In Finland, all healthcare providers are obliged by law to upload patient health information to the National Patient Data Repository.<sup>(19)</sup> A small subset of the data is sent to the repository as structured data, with the bulk of the data stored as free text.<sup>(19)</sup> The proposed patient summary will be based on the structured data in the national repository. Patient data is retrieved from the National Patient Data Repository using the single national identifier, the National Social Security Number, which is used for all purposes including health. My Kanta, the Finnish National online patient portal, provides patients with a range of services including the ability to see—at organisational level—who has accessed their data in the repository. The Finnish national standard for a patient summary has been defined, including diagnoses, allergies, procedures, laboratory results, and images. Two approaches to the generation of the Patient Summary are under consideration: implementing a single document or creating a dynamic Patient Summary from the items in the National Patient Data Repository. The latter gives a better result, but takes longer and is more difficult. Therefore, it is suggested that, in hindsight, implementing the former—a single document—demonstrates at an early stage the potential benefits of the patient summary.

## Conclusion

Each country reviewed had identified the need for a succinct summary of a patient’s key clinical information to be available to authorised healthcare practitioners during episodes of unscheduled care, such as treatment at an out-of-hours clinic or emergency department. Experts in every country emphasised the need for a unique national health identifier as a crucial prerequisite for any patient summary implementation—a demographics database using this health identifier typically in place well in advance. Stakeholder engagement was considered to be a critical workstream and significant time and resources were devoted to

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engaging the support of all stakeholder groups. In most countries, governance typically took the form of a national programme board, often chaired by a clinical lead and with representation from key stakeholder groups, such as professional bodies representing clinicians. Clinical buy-in was considered critical and, on the successful standalone programmes in Scotland and Northern Ireland, success tended to be measured through clinical success stories and critical incidents, together with pragmatic audits to give an overview of key indicators. For example, in Scotland, the use case—emergency care only—was tightly controlled and requirements were defined with a view to ‘getting everyone on board’.<sup>(9)</sup> Emphasis was placed on maximising use of existing systems, as well as simplicity, fitness for purpose, and a restrained approach.<sup>(9)</sup> Practical considerations for implementation were also emphasised. Where the patient summary is implemented as a standalone system, interfaces should be well-integrated with current systems to avoid an adverse impact on healthcare professionals—such as creating the need to enter security credentials twice or creating extra workload for GPs.<sup>(13)</sup> A minimum number of patient summaries must be available in the system—approximately 50% coverage—otherwise, healthcare professionals tended to abandon use of the system. It should also be possible to retrieve and read a patient summary in 30 seconds or less, otherwise the system is not practical—for example, for the ambulance service. In Scotland and Norway, patient summaries were shown to be particularly beneficial for unconscious patients, for patients using multiple pharmaceutical products, and for patients with a history of substance abuse.<sup>(6)</sup>

## Chapter 1 Introduction

The purpose of this document is to review best practice from national implementations of electronic summary care records in a number of countries. Electronic summary care records provide the treating healthcare professionals with a succinct summary of a patient's essential clinical information during episodes of unscheduled care, thereby improving patient safety and the quality of care. Together with ePrescribing, electronic summary care records are considered to be a crucial and 'immediate' element of support for community care in the Slaintecare Implementation Strategy, which implements the ten-year, cross-party vision for healthcare in Ireland. The findings of this review will form the evidence base for a set of recommendations to the Minister for Health on the implementation of a national electronic patient summary in Ireland.

### 1.1 Background

The best practice review in this document was performed as per HIQA's legislative remit under the Health Act 2007 and subsequent amendments to the Act.<sup>(20)</sup> Under the Health Act 2007, HIQA has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information.<sup>(20)</sup> The responsibilities of HIQA in this regard are outlined in the following sections of the Act:<sup>(20)</sup>

- 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)
- Section 8(1)(k): to set standards as HIQA considers appropriate for the HSE and service providers respecting data and information in their possession in relation to services and the health and welfare of the population
- Section 8(1)(l): to advise the Minister for Health and the HSE as to the level of compliance by the HSE and service providers with the standards referred to in paragraph (k).

Under Section 8(1)(i) of the Health Act 2007, HIQA is charged with evaluating information respecting the service and the health and welfare of the population.

The Slaintecare Implementation Plan, published in August 2018, states that “ICT has the potential to be the biggest and most effective driver of change and improvement for better patient outcomes across the health system.”<sup>(2)</sup> The plan identified as a priority the design and roll out of a range of primary—and community—based ICT services that will improve the lives of patients, including ePrescribing and summary care records as immediate systems.<sup>(2)</sup> Shared care records will also provide a means for integration of community-based care and the acute hospital sector, supporting that sharing of patient data across health and social care settings.<sup>(2)</sup>

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

- published an international review summary care records (2016)<sup>(21)</sup>
- published clinical datasets for diagnosis, allergies, and procedures<sup>(22,23,24,25)</sup>
- contributed to the implementation of the EU cross-border summary (OpenNCP)
- developed National Standard on Information Requirements for a National Electronic Patient Summary in Ireland (2019).\*

In particular, the National Standard on a National Electronic Patient Summary in Ireland (2018) defined the clinical dataset for the clinical data that would be exchanged as part of a national Irish implementation: subject of care, health conditions, procedures, allergies, vaccinations, and medications. A number of approaches to the implementation of a national electronic patient summary, conformant to this Standard, are now under consideration.

One such approach is the implementation of an electronic clinical summary produced by the patient’s GP, uploaded and available centrally for the unscheduled care use case. The introduction of a national, electronic patient summary forms part of the larger, long-term

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\* 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.

programme that includes shared care records and, ultimately, a national electronic health record.

This document describes best practices in the national implementations of electronic patient summaries from a number of exemplar countries. Its findings are intended to inform the discussion around the implementation of a national electronic patient summary in Ireland. Relevant learnings regarding the relationship between shared care or electronic health records and national electronic patient summary implementations are thus included.

## 1.2 Key terms

During the development of Recommendations on the implementation of a National, Electronic Patient Summary in Ireland, HIQA identified the need to clarify key terms used:

- Patient Summary
- Shared Care Record
- Electronic Health Record
- Patient Portal

Informed by research undertaken by the Irish Platform for Patient Organisations, Science, and Industry (IPPOSI) and by others, HIQA has reviewed usage of these terms. The term 'Electronic Health Record' is used to describe electronic records of care in a number of different settings, such as a hospital-wide record of care, a record of care from a GP service, or a regional record of care. In fact, electronic records of healthcare were described using combinations of the words 'shared', 'electronic', 'care', 'medical', 'summary', 'patient' — for example, the following terms were used in one academic paper:

- shared electronic patient records
- electronic summary record
- shared electronic patient summary
- shared summary record

The National Electronic Health Record is sometimes called a 'shared record' because of the different Electronic Health Record (EHR) systems (Acute EHR, Community EHR) and other systems that will share information to create the overall national record.

To ensure clarity and consistency, it is strongly recommended that the terms (National) Electronic Health Record, Patient Summary (summary care record), Shared Care Record,



and Patient Portal be used by health stakeholders with the meanings defined in this document.

### 1.2.1 Patient Summary

A Patient Summary is a summary of the main parts of an Electronic Health Record that will be most useful to a healthcare professional treating a patient without access to the patient's records (for example, on holiday, visiting friends or on a business trip).<sup>(1)</sup> This summary assumes that the healthcare professional needs to rely on the information in the absence of any local health records for this patient.

A Patient Summary is not the same as a Shared Care Record or an Electronic Health Record.<sup>(1)</sup> It is often a sub-set of a patient's record, most often extracted from the patient's GP system, which is usually the most complete record on a patient, but may in the future be extracted from a National Electronic Health Record. In several countries, the implementation of a summary care record for unscheduled care was the first step toward a National Electronic Health Record.<sup>(9,26)</sup>

The Northern Ireland Emergency Care Summary is a Patient Summary that was introduced between 2008 and 2012. Clinicians can view the Northern Ireland Emergency Care Summary through the Northern Ireland Electronic Care Record.<sup>(27)</sup> The Northern Ireland Emergency Care Summary provides details of the patient's current medications and any known allergies, as well as necessary demographic information to support safer treatment during episodes of emergency care.<sup>(28)</sup> The Northern Ireland Emergency Care Summary is populated by information uploaded twice daily from GP practice systems. Implementation of the Northern Ireland Emergency Care Summary also provided the first opportunity to understand key aspects of national implementation of electronic health records—for example, through the identification and resolution of issues with nationally held demographic information for patients.<sup>(12)</sup>

The Slaintecare Implementation Plan considers the introduction of summary care records in Ireland to be such a step.<sup>(2)</sup> In 2018, the National Standard on Information Requirements for a National, Electronic Patient Summary for Ireland was published.<sup>(29)</sup> The Standard defines the clinical content for the summary: demographic information, medication, allergies, health

conditions, procedures and vaccination information. HIQA is developing a corresponding set of Recommendations on the implementation of a National, Electronic Patient Summary.

### 1.2.2 Shared Care Record

A Shared Care Record enables healthcare providers in different settings—for example, primary care and hospitals—to view patient records for direct patient care.<sup>(1)</sup> It brings together information from various systems into a single place for care professionals to use to support the delivery of care.

The Northern Ireland Electronic Care Record is an example of a shared care record, bringing together information from existing electronic record systems in hospitals and clinics throughout Northern Ireland.<sup>(30)</sup> The clinical information in the Electronic Care Record system can include the Emergency Case Summary (current medications, known allergies, medications), lab tests, x-rays, referrals, investigation requests, appointments, encounter and discharge letters from various HSC systems. Where a patient's GP decides it to be appropriate, patients with a long term health condition will also have a Key Information Summary on the Northern Ireland Electronic Care Record, containing details about patients' health, including any long term conditions, agencies involved with the patient, list of care plans or self-management plans, the patient's preferred treatment arrangements, resuscitation status and whether an Advance Decision to Refuse Treatment (ADRT) is in place.

The Northern Ireland Electronic Care Record was launched in 2013, with the pre-existing Northern Ireland Emergency Care Summary integrated into it. Implementation of the Northern Ireland Electronic Care Record provided an opportunity to re-use existing systems where possible and to evaluate those systems, informing the development of future strategies including any necessary upgrades or replacements.<sup>(26)</sup>

Within the context of the development of a National Electronic Health Record for Ireland, a National Shared Care Record will be created first, to combine patient data from individual organisation's IT systems into a single patient record.<sup>(2)</sup> This National Shared Care Record is likely to use existing clinical records which can be accessed remotely but stored locally. Where the National Electronic Patient Summary exists, it can be integrated into the National Shared Care Record.

### 1.2.3 Electronic Health Record

An Electronic Health Record (EHR) contains the information documented by healthcare professionals when they interact with that patient—for example, the patient’s symptom history, past history of illnesses and operations, clinical observations made by the professional such as a blood pressure reading, blood and other test results, X-rays and scan results, prescriptions and other treatments, care advice, the course of the illness, preventive and public health activities such as immunisations, and activities undertaken by patients to stay healthy.<sup>(1)</sup> An EHR system can support healthcare professionals by facilitating for example, the use of checklists, alerts, and predictive tools, and embedding clinical guidelines, electronic prescribing and the ordering of tests.

In Northern Ireland, the Encompass initiative is intended to provide a full electronic health record—that is, a single patient record, which can be securely accessed, recorded, and shared in real time by healthcare professionals treating the patient.<sup>(31)</sup> Replacing the Northern Ireland Electronic Care Record, Encompass will contain all of the patient’s medical notes, prescribed medications, tests ordered, and referrals made and received. Patients (and their carers) will be also able to book appointments, review test results, and communicate with those providing their care. In this way, it replaces many existing systems that are linked to the Northern Ireland Electronic Care Record at present, and which are due for replacement owing to age or lack of capacity.<sup>(26)</sup>

The ultimate goal of the National Electronic Health Record programme is similar—a National Electronic Health Record for each citizen in Ireland. That is, a complete digital record of a patient’s journey, from cradle to grave, across all health and social care settings.<sup>(1,2)</sup> The National Electronic Health Record will draw information from a wide range of healthcare organisations in Ireland – such as laboratories, specialists, medical imaging facilities, pharmacies, emergency facilities, primary, secondary, and tertiary care, public health, community care, and social care – to provide the most complete information available to the authorised healthcare professional caring for the patient in the patient’s National Electronic Health Record. The patient’s National Electronic Health Record then becomes the single source of truth for all their care information.

The National Electronic Health Record has been identified in Ireland as a core capability required for the future delivery of healthcare in Ireland.<sup>(1)</sup> It will move Ireland from the

current position where patient records and key information are locked in paper files and within specific organisations, to an environment where digital patient records are shared securely across care settings with appropriate consent.

It should be noted that the term Electronic Health Record (EHR) is used to describe electronic records of care at a number of different levels—for example, the record of a patient's care from a particular healthcare service or the hospital-wide record of a patient's care.<sup>(1,32)</sup> Or it can be used to describe a much fuller record of the patient's healthcare regionally, nationally, or across international borders. The following terms are also in use, though they are also sometimes called Electronic Health Records (EHRs):

- Electronic Patient Record (EPR): sometimes refers to a longitudinal record of care, about a single individual and held by a provider within a single care organisation. For example, Project Oak in St James' Hospital is an Electronic Patient Record, providing a complete record of the patient's care within the St James' hospital organization.<sup>(33)</sup>
- Electronic Medical Record (EMR): this term arose out of the HIMSS certification model, and so is more commonly used in the United States of American. It does not imply a single site implementation, but frequently is single site. A local example is the electronic care record in the Galway clinic, which meets HIMSS EMR Adoption Stage 6 of the HIMSS Electronic Medical Record Adoption Model—briefly described in Appendix A.<sup>(34)</sup>
- Personal Health Record (PHR): a term often used to describe records that are usually created and maintained by individuals themselves using a mobile app and are not usually linked up with healthcare system Electronic Health Records (EHRs).<sup>(1)</sup> For example, the Health app on Apple's iPhone allows an individual record personal health information such as date of birth, medical conditions, allergies, medications, blood type, and so on.<sup>(35)</sup>

Many countries have put a National Electronic Health Record in place. For example, the Spanish Autonomous Region of Andalusia implemented a full electronic health record for all of its citizens in the early 2000s, providing a comprehensive lifetime record of their health and social care. In Norway, a National Electronic Health Record was introduced on a phased basis, with pilot implementations taking place in the different health regions ahead of national rollout. The Norwegian Electronic Health Record provides a comprehensive record of a citizen's healthcare over their lifetime. The similarly comprehensive Estonian National

Electronic Health Record was implemented on the national eServices infrastructure which was developed during the 1990s.

Implementation of a National Electronic Health Record falls within the remit of eHealth Ireland. The overarching ambition of the National Electronic Health Record strategic programme is to deliver a single national health record, spanning acute and community care.<sup>(36)</sup> Information from acute and community settings, together with information from other settings, will be integrated into the National Shared Care Record, which will ultimately evolve into the National Electronic Health Record for Ireland. Progress is already being made, with the Slaintecare Implementation Plan noting the rollout of the Maternal and Newborn Clinical Management System (MN-CMS) in Cork in 2016 and Kerry and the Rotunda in 2017 as significant milestones.<sup>(2)</sup> Both implementations were part of the Maternal and Newborn Clinical Management System (MN-CMS) project.<sup>(37)</sup>

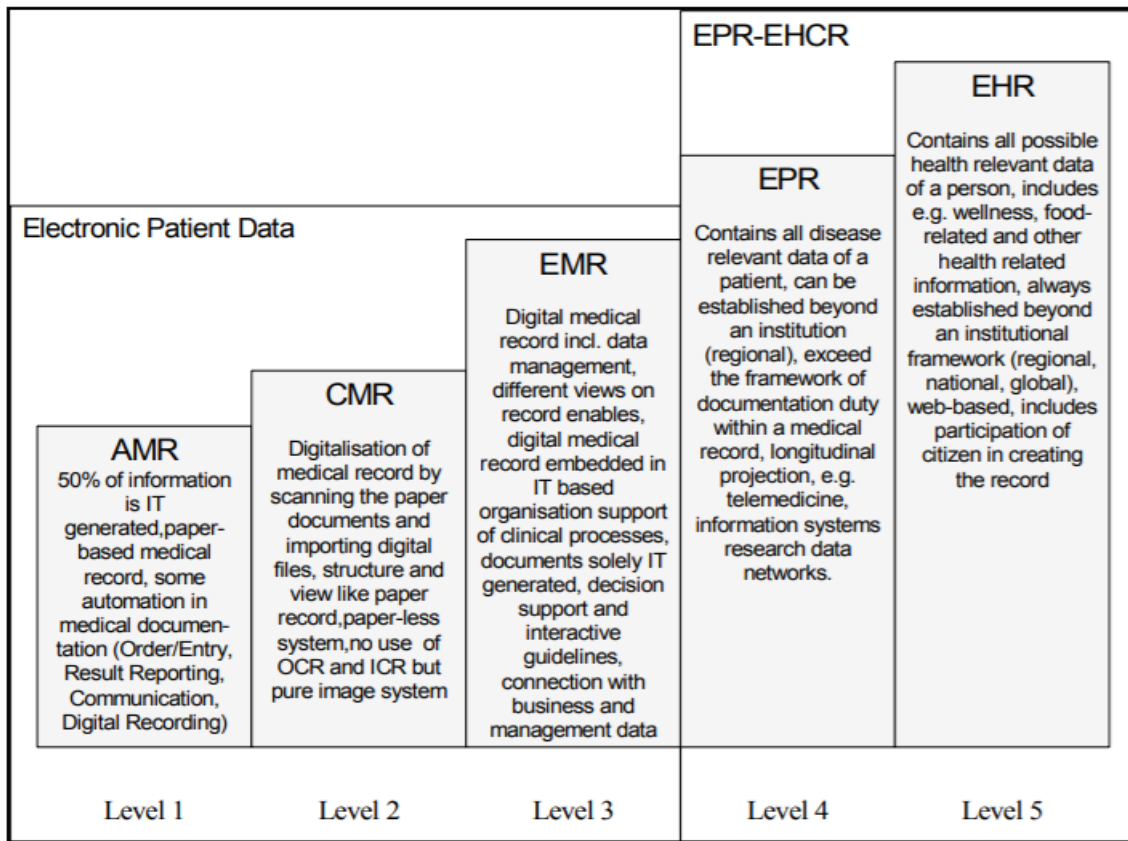
#### **1.2.4 Patient Portal**

A patient portal is specially created to allow online access for individuals to their own healthcare information through apps on their smartphone or other devices, or using a Website.<sup>(1)</sup> In many countries, patients use a patient portal to access to their Electronic Health Record, where they can see their latest test results, clinical correspondence, request repeat medications and to request appointments. Some patient portals also enable patients to add their own health information, to maintain their own record of home monitoring for conditions such as diabetes. In another example, the Record may provide a parent with the ability to add supplementary entries to an incomplete vaccination record for their child. The clinician reviewing the record can then review these and the original entries to gain a better understanding of the child's vaccination history. The National Patient Portal is expected to give patients access to their National Shared Care Record, and later to their National Electronic Health Record.

### 1.2.5 Theoretical Framework for Electronic Healthcare Records

The EU EHR Impact report from 2008 provides a crucial starting point for understanding the term Electronic Health Record.<sup>(32)</sup> The report relied on the following classifications of **Electronic Healthcare Records (EHCR)** from the Medical Records Institute from the lowest to the highest level of sophistication:

Table 1: Five Levels of Electronic Healthcare Records (EHCR)



Source: adapted from Waegemann (2002) and Blobel B (2003)<sup>32</sup>

\* AMR is defined as an Automated Medical Record, while CMR is defined as a Computerised Medical Record.

Therefore, Electronic Health Records were defined as ‘...repositories of electronically maintained information about individuals’ **lifetime** health status and healthcare, stored such that they can serve the multiple legitimate users of the record...’.

This was considered to be a rather idealistic definition, with such systems implemented at regional or organisational level. In fact, a comprehensive Electronic Health Record was likely to require ‘...an interoperable system connecting partial EHRs stored at various healthcare providers and other actors will be necessary.’ The term EHR system was preferred, as it

could ‘... include parts of a comprehensive [EHR] record, allow limited sharing, or be focused on a particular health service provider organisation rather than all the health-related data about people.’


The report went on to define an Electronic Health Record in terms of another key characteristic—the level of interoperability at which it functions:

1. **Availability/access to stand alone solutions:** having a [standalone] Electronic Health Record (and/or ePrescribing) solutions
2. **Potential for interoperability:** use of standards and set up allowing information to be shared, but no actual exchange taking place
3. **Real inter-operation:** using the interoperability features—exchange and share information and knowledge with other actors in the system for the purposes of collaboration, thus changing working practices and roles, multi-disciplinary teams, and so on:
  - i. **Local connectivity**
    - i. people within teams (wards, departments on one site): doctors, other health professionals, management and administrative actors, informal carers, citizens/patients
    - ii. people between teams (wards, departments on one site)
  - ii. **Multi-site connectivity:** within a multi-site organisation entity
  - iii. **Regional connectivity:** between organisation entities within a region
  - iv. **National connectivity:** between organisation entities within a country
  - v. **Multi-national connectivity:** cross border and cross Member State

Interoperability across primary care, secondary care and other settings adds a further layer of complexity—for example, an Electronic Health Record used in all acute hospitals is another facet of interoperability.

Thus, the term Electronic Health Record can legitimately (and confusingly) be used to describe a system used within a hospital, within a region, nationally, or across national borders. Additionally, the term ‘Electronic Health Record’ tends to be used in media reports and even in every day speech, to refer to any kind of Electronic Healthcare Record—the umbrella term for all levels in the EHR Impact model from an Automated Medical Record (level 1) to a full Electronic Health Record (level 5).

Additionally, the Healthcare Information and Management Systems Society, Inc. (HIMSS) has defined the following adoption model for electronic medical records:<sup>(38)</sup>

STAGE	 EMR Adoption Model Cumulative Capabilities
7	Complete EMR; External HIE; Data Analytics, Governance, Disaster Recovery, Privacy and Security
6	Technology Enabled Medication, Blood Products, and Human Milk Administration; Risk Reporting; Full CDS
5	Physician documentation using structured templates; Intrusion/Device Protection
4	CPOE with CDS; Nursing and Allied Health Documentation; Basic Business Continuity
3	Nursing and Allied Health Documentation; eMAR; Role-Based Security
2	CDR; Internal Interoperability; Basic Security
1	Ancillaries - Laboratory, Pharmacy, and Radiology/Cardiology information systems; PACS; Digital non-DICOM image management
0	All three ancillaries not installed

Healthcare Information and Management Systems Society, Inc. (HIMSS) is a global, non-profit organization with expertise in health innovation, public policy, workforce development, research and analytics. It provides advice on best practices in health information and technology to global leaders, stakeholders and influencers.



### 1.2.6 Individual Health Identifier

The Individual Health Identifier (IHI) is a national health service identifier that will be used as the single number for identifying a patient by all of the Electronic Health Record systems across healthcare organisations in Ireland.<sup>(1)</sup> The use of a single identifier is an important way to ensure that the correct information on each patient is combined into the national record, and avoids data on the wrong patient being sent.

An IHI is being introduced in the Irish Health Service and an IHI office has been established. The IHI is the unique number, used only within systems, that will be used to safely identify an individual and their health information when using a health or social care service—for example, hospitals, GP offices, clinics. The IHI is only used as an identifier, it does not contain any medical information.

## 1.3 Types of implementation

National implementations can be categorised in one of three ways: top-down implementations, bottom-up implementations, and middle-out implementations.<sup>(5)</sup>

### Top-down implementation model

Sometimes known as the 'Cathedral' implementation, a top-down implementation is defined as a large scale, top-down, highly standardised approach to implementation. An example is the English National Health Service implementation of summary care records: the now-defunct National Programme for Information Technology aimed to create a single shared electronic health record, stored centrally, which all healthcare providers view and update. The English health system is unusual internationally, with the National Health Service acting as a national, single-payer health system with highly centralised governance and management. This allowed the adoption of a highly centralised approach to architecture, standards compliance, and procurement process.

The 'top-down' approach often means that non-compliant local systems are shut down in favour of new systems that were less suited to the local environment, that may necessitate staff retraining and workflow adjustments, and that may increase the risk of errors in care. Requirements are not easily changed—for example, allowing a patient to attend more than one GP would require substantial change—necessitating workarounds to accommodate

emerging needs. A top-down implementation can force local providers to adopt short term workarounds and, over time, can become almost unworkable. Undertaking a large-scale project that may only show returns in the medium to long-term also means that the project misses out on demonstrating the benefits, and motivating stakeholders, early in the project. This approach could be characterised as meeting the needs of national governments but possibly at the expense of local providers.

### **Bottom-up implementation model**

Also known as the 'Bazaar' approach, the bottom-up model is an organic, laissez-faire approach to implementation. The United States has a highly fragmented and decentralised health system and so has adopted a 'bottom-up' approach. Regional coalitions of service providers seek to interconnect their existing systems into Health Information Exchanges, which are expected to eventually form a national system. This approach provides virtual views of records, abstracted or aggregated from regional systems.

The 'bottom-up' approach is more resilient in adopting new technologies. However, it may result in a weaker national system with data holes and data quality problems. Standards development may be seen as largely voluntary and local systems are thus less likely to align with national policy goals. Additionally, standards development in health IT is less likely to attract significant resources. This approach could be seen as meeting the needs of local providers but at the expense of national needs.

### **Middle-out implementation model**

The middle-out implementation approach seeks to reconcile the different starting points, goals, and resources of government and local providers. Government, industry, and clinicians collaborate to create national standards for interoperability and to encourage compliance. Customised interfaces can be created for existing systems, while new systems specifications can also comply as far as possible. The integration costs are similar to the bottom-up approach but the result is a richer and higher quality capability for information sharing. It can also help to avoid the situation where systems are locked into proprietary software and standards. The middle-out approach is seen as flexible, technically robust, and cost effective.

It was concluded that, if the English National Health Service moved from a top-down to a middle-out approach, it would not be locked into a central architecture or into defining local systems. Instead it might consider defining how those systems interoperate and implementing a virtual, rather than an actual, electronic health record. If the US health system moved from a bottom-up approach, instead of implementing the same system, it could define an evolving set of standards that brings public and private local and centralised systems into a functional national implementation.

**Note.** All the other countries included in the review, with the exception of England, could be considered to have adopted a middle-out approach—that is, to have defined national standards and set overall direction, rather than allowing the programme to be driven entirely by local needs (bottom-up model) or by government needs (top-down model).

## 1.4 Irish context

Electronic summary care records are considered to be a crucial and immediate element of support for community care in the Slaintecare Implementation Plan (2018).<sup>(2)</sup> The Plan aims to achieve fully integrated healthcare in Ireland, noting the impossibility of achieving this goal without a National Electronic Health Record.<sup>(2)</sup> It also recognises the role of shared care records in achieving this vision.<sup>(2)</sup> Additionally, Ireland is participating in the EU OpenNCP programme and thus has commitments in respect of the facilitation of cross-border exchange of ePrescriptions and patient summaries.<sup>†(2)</sup>

As part of its Open National Contact Point implementation roadmap, Ireland successfully participated in a five week event, with ten other European Union countries in November 2019, to test the interoperability of each Member State's national contact point. During the event, each Member State used their own representative test data (conformant to the Clinical Document Architecture Standard), their supporting infrastructure and their capability to provide valuable information to a healthcare professional to treat a patient as per the patient summary and ePrescription use cases defined in 2011/24/EU directive. Ireland is currently scheduled to make patient's electronic patient summaries and electronic prescriptions available to other participating countries in October 2020.

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<sup>†</sup> The Open NCP project supports the transfer of Irish citizen's data relating to electronic patient summary and electronic prescriptions information for unscheduled care with participating member states. The goal is to enhance the continuity of care for individual citizens using a secure patient consent service and provide safe and high-quality transfer of healthcare information within EU member states in accordance with EU Directive 2011/24/EU.

This review looks at how other countries have introduced a national electronic summary care record directly comparable to the use case in the Irish National Standard.<sup>(29)</sup> Given the small number of comparable national implementations, the review also looks at how exemplar countries addressed this use case. An accompanying AS IS review examines the current Irish landscape using the themes of governance, stakeholder engagement and implementation. Informed by the AS IS review, this review outlines the relevant considerations for the success of the national implementation programme for electronic patient summary in Ireland.

## 1.5 Methodology

An initial desktop scoping review indicated a huge variation, globally, in the implementation of summary care records, with few examples of national implementations that were directly comparable to the Irish situation. Summary care records were often implemented as part of, or a precursor to, more extensive shared care record and electronic health record implementations. This reflects the longer term vision for eHealth in Ireland, outlined in the Slaintecare Implementation Strategy, which encompasses summary care records and shared care records as part of the journey toward electronic health records.

Therefore the focus of the review has been broadened to evaluate how the patient summary use case has been addressed in each of the countries assessed—whether through a national electronic patient summary as stand-alone system, but also in relationship to shared records and electronic healthcare records. This review also focuses on best practice within implementations. Academic evaluations, where available, were included but higher emphasis was placed on the experiences of those at the frontline of programme management for the national implementations.

A range of countries was selected, of broadly similar size (population between 1 and 8 million) with well-established eHealth programmes and at various stages of development in addressing the use case. Given the depth of material available, the English summary care records programme was also chosen—with population of 51 million at the time of implementation, significantly larger in scale. Countries considered to be world leaders in the implementation of eHealth were also given priority. The selection of countries for further

study depended heavily on the availability of accurate information in English, within the timeframe available.

Telephone interviews were held with experts from the ten countries selected: England, Scotland, Norway, Austria, Denmark, Estonia, Finland, Spain (Andalucía), and Northern Ireland. During these calls, the implementations were explored under the following themes:

- Clinical content included
- Implementation model, together with information sources
- Implementation phases
- Patient involvement – later expanded to encompass engagement of all stakeholders
- Governance, including the legislative and regulatory framework and information governance
- Lessons learned from the implementation programme

Four countries were selected for in-depth review, which examined their respective experiences under the themes mentioned:

- one large scale implementation (England), and
- three countries of comparable size with well-established programmes (Scotland, Northern Ireland, and Norway)

Where relevant, isolated findings from the other countries were also incorporated into the discussion of the respective theme. Finally, the review analysed the findings for each theme and drew conclusions to inform the implementation of national electronic patient summaries in Ireland.

## Chapter 2 England

The overall aim of the original summary care record programme was to create a national electronic summary care record for every English citizen in the population of 51 million, as part of the larger National Programme for Information Technology programme.<sup>(3)</sup> The original summary care record listed medications, allergies, and adverse reactions. When the programme was well established, the summary care record was updated to allow the inclusion of an Additional Information dataset.

Over 55.2 million summary care records have been created—covering 98% population—in over 99% GP practices in England. Over 700 summary care records are viewed every hour. Summary care records are 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 patient guided to a more appropriate care pathway.

One participant stated “While I use summary care record relatively infrequently, on every occasion it has directly informed, changed and better aided patient care, it counts enormously”.

Once the summary care record programme was well-established, other requirements were considered and, in 2014, an Additional Information capability was introduced. The summary care record with Additional Information captures significant medical history, reason for medication, anticipatory care information, end of life care information, and immunisations, as well as the standard summary care record clinical content. By 2018, over 98% of GP practices had the capability for a summary care record with Additional Information, but only about 2.4% of English citizens had the record. It was considered particularly useful for frail and elderly patients.

A national demographics database and messaging service, known as the Spine, was considered to be an essential prerequisite for the national summary care record programme,

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together with a new network and new electronic prescribing service. Pilot projects took place in two localities in 2007, while the national rollout began in 2009.<sup>(3)</sup> The programme encountered a number of early challenges—British Medical Association raised concerns very publicly in 2010, while civil liberties groups also challenged the consent model. A large scale evaluation and two smaller inquiries ultimately led to the adoption of a smaller clinical dataset and a simplified consent model, which seemed to allay the concerns of both sectors.

Table 1 – Implementation of the English summary care record

Date	Patients with summary care record	Summary care records viewed	Event
1997 - 2006	0	0	<p><b>Preparation</b></p> <ul style="list-style-type: none"> <li>NHS IT information strategy developed.</li> <li>National Programme for Information Technology launched.</li> <li>NHS Connecting for Health established.</li> <li>Ministerial Taskforce makes recommendations.</li> </ul>
2007	0.1m	0	<ul style="list-style-type: none"> <li>Summary Care Record Advisory Group established.</li> <li><b>First summary care record.</b> Uploads typically took one week.</li> <li><b>NHS Spine operational</b> as a demographic database.</li> <li>National media campaign 'the big opt out' launched, urging citizens to refuse to have a summary care record.</li> </ul>
2008	0.2m	0	<ul style="list-style-type: none"> <li><b>Summary care record pilot in six Primary Care Trusts.</b> Approx. 150,000 summary care records created.</li> <li>First evaluation of the programme published, leading to the 'permission to view' consent model.</li> </ul>
2009	1.0m	11,848	<ul style="list-style-type: none"> <li><b>National rollout of summary care records</b> began.</li> <li>Public information campaign also launched.</li> </ul>
2010	4.1m	27,314	<ul style="list-style-type: none"> <li>British Medical Association calls for summary care record <b>programme suspension</b>, over concerns around patient consent.</li> <li>Formal evaluation of the programme, showing partial success.</li> <li>Two subsequent reviews recommended changes to clinical content and information governance respectively.</li> </ul>
2012	21.9m	228,261	<ul style="list-style-type: none"> <li>Summary care record business case fully approved.</li> </ul>
2013	32.5m	663,205	<ul style="list-style-type: none"> <li>Health and Social Care Information Centre (HSCIC) replaced National Health Service Connecting for Health.</li> </ul>
2014	48.6m	1.7m	<ul style="list-style-type: none"> <li>Summary care record included in <b>GP Contract</b>.</li> <li><b>Spine 2 fully operational</b>, managed by Health and Social Care Centre.</li> <li>Smart cards rolled out.</li> <li>Expert Advisory Committee oversees the expansion of the summary care record with Additional Information.</li> </ul>
2015	55.1m	4.2m	<ul style="list-style-type: none"> <li><b>National rollout to community pharmacies</b> begun.</li> </ul>



			<ul style="list-style-type: none"> <li>• First summary care records in ambulances.</li> <li>• Negative coverage in national media around data security.</li> </ul>
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## 2.1 Governance

Led by the Secretary of State for Health, the Department of Health provides strategic leadership for healthcare in the UK, while National Health Service England is responsible for the day-to-day delivery of health services across England, including the summary care record programme.<sup>(39,40)</sup> The summary care record implementation was part of the National Health Service information and technology (IT) programme, where the National Health Service Care Records Service was considered to be the cornerstone.<sup>(4)</sup> The service was in two parts—a centrally stored summary care record and a locally held, shared electronic health record, with summary care records piloted first.

The National Health Service England Summary Care Record programme is considered to typify a top-down implementation— defined earlier in Types of implementation on page 25— as a large scale, top-down, highly standardised approach to implementation.<sup>(5)</sup> The English health system is unusual internationally, with the NHS acting as a national, single-payer health system with highly centralised governance and management.<sup>(5)</sup> This allowed the adoption of a highly centralised approach to architecture, standards compliance, and procurement process.<sup>(5)</sup> By its nature, a top-down implementation is considered to meet the needs of Government but often at the expense of local needs—for example, where local systems are replaced rather than adapted or where short-term workarounds to meet national needs lead to an unworkable solution over the long-term.<sup>(5)</sup>

The English Department for Health developed a detailed implementation plan, with a centrally coordinated monitoring scheme.<sup>(3)</sup> The initial implementation programme of the English summary care record was initiated by the Government and the IT industry, and led by a senior civil servant.<sup>(9)</sup> A large investment was made with the intention of developing a national IT infrastructure.<sup>(9)</sup> Requirements were defined through technical model, with feedback solicited from defined stakeholder groups.<sup>(9)</sup> Change was tightly managed by the civil service.<sup>(9)</sup> Clinicians were seen 'as a hurdle to be overcome'.<sup>(9)</sup> The Communications Department of Connecting for Health, the fore-runner of NHS Digital set the 'house style' and coordinated communications.<sup>(9)</sup> Academic evaluations of the programme point to the

difficulties inherent in this approach, though the scale of the implementation in itself would create significant challenges for any implementation.<sup>(3,9,41)</sup>

The governance structure for the original summary care record programme was centralised, including the following bodies:

- National Programme Board, which oversaw the whole National Programme for Information Technology.
- Summary Care Record Programme Board, the main governance body for the programme.
- National Clinical Reference Panel, which oversaw the clinical content of the summary care record.
- Summary Care Record Advisory Group, which was established in 2007 as part of the Ministerial Taskforce Report on the Summary Care Record.
- National Information Governance Board, established in 2007, oversaw the summary care records plus other elements of the Care Records Service. It replaced National Health Service Care Records Programme Board.

As noted earlier, the English Department for Health developed a detailed implementation plan, with a centrally-coordinated monitoring scheme.<sup>(3)</sup> The Connecting for Health organisation was subsequently replaced by the Health and Social Care Information Centre, and later by the National Health Service Digital organisation.<sup>(3)</sup> Following statutory change early in 2007, responsibility moved from the Connecting for Health organisation, to the Strategic Health Authorities.<sup>(41)</sup> As these structural changes occurred, the governance structure for the summary care record also evolved.<sup>(3,41)</sup>

In 2010, an Expert Advisory Committee was established to ensure that any proposed expansion of the summary care record content would be analysed by representatives of patient, public, and clinical professional bodies together, with any resulting recommendations of expanding from urgent to non-urgent care.<sup>(42)</sup> As part of the rollout in each trust, an individual in management with Caldicott Guardian rights was employed as a privacy officer. The privacy officer was asked to reconcile summary care records against the PAS systems (for example) on a monthly basis—for example, to identify if a summary care record had been viewed in a hospital but the patient hadn't visited—and then required to follow up any discrepancies. Typical breaches concerned people looking at their own

summary care records. The Information Commissioner's Office (ICO) was also consulted about the terms of reference.

Under the current consent model, summary care records are optional, a patient can choose to have one or not and they can change their mind at any time by contacting their GP practice. Summary care records are accessible only with permission from the patient except for exceptional circumstances, such as emergency access if the patient is unconscious. No other healthcare setting can update the summary care record apart from the patient's GP practice.

## 2.2 Implementation

A national demographics database was considered to be an essential prerequisite for the national summary care record programme, with the Spine infrastructure used for this purpose. Each fully-registered active National Health Service patient is eligible for a summary care record, which is stored in the Spine. Records in GP practice management systems are usually coded, typically with Read codes and/or SNOMED codes. Core data items taken from the GP record are:

- allergies and adverse reactions
- acute medication – prescribed in last 12 months
- repeat medication – all from the current practice
- discontinued repeat medication – all medications stopped in the last 6 months

The evolution of the clinical content dataset is shown in Appendix A.

When the core data items in the GP record are updated—triggered by use of the physician's smart card—the summary care record is automatically updated in real time. Specific events trigger the update—for example, prescribing a broad spectrum anti-biotic and a nasal spray—but others do not—for example, being bitten by a dog. But, where a trigger does not exist, the information can be added manually. The update is saved to the patient's summary care record, using the patient demographics to match the record in the Spine.

When summary care records were first implemented, an overnight batch job was scheduled for the GP practice or supplier and all updates were sent to the Spine overnight—with an

average of 5,000 patients in each GP practice. Implementation stalled around 20 million for a time. A lot of areas lacked resources locally.

In 2014, the summary care record with Additional Information was introduced, capturing significant medical history, reason for medication, anticipatory care information, end of life care information, and immunisations. Each patient is assigned a summary care record by default but must request the Additional Information capability. The Additional Information capability increases the number of trigger points to update the summary care record as part of the practice batch job.

Views of summary care records with Additional Information increased each year since 2014, but adoption has been slower than for the original summary care record.

**Table 2 – Usage of English summary care record with Additional Information**

Year	Views per week
2014	20,000
2016	60,000
2017	100,000
2018	120,000
2019	160,000

By 2018, over 98% of GP practices had the capability for a summary care record with Additional Information. However, only about 2.4% of English citizens have Additional Information.

**Note.** The evaluation report on the Early Adopter Programme, titled 'The Devil's in the Detail' provides rich detail about the challenges faced on each of the early adopter sites as well as the measures that proved successful in encouraging adoption.<sup>(41)</sup>

## 2.3 Lessons learned

The English summary care record was also introduced to address:

'...unscheduled care settings where little or no other information about the patient was available (for example when there was loss of consciousness, confusion or communication

difficulties; or when the person was away from home and did not know what medication they were on)... Designers and policymakers saw the potential for extending the content of the summary care record further—for example, by creating the facility for staff in walk-in centres, out-of-hours centres, ambulance service and community services to add details of encounters or test.<sup>(41)</sup>

The overall aim was to create a national electronic summary care record for every English citizen in the population of 51 million, as part of the larger National Programme for Information Technology programme.<sup>(3)</sup> Pilot projects took place in two localities in 2007, while the national rollout began in 2009.<sup>(3)</sup> The programme encountered a number of early challenges—British Medical Association raised concerns very publicly in 2010, while civil liberties groups also challenged the consent model. A large scale evaluation and two smaller inquiries ultimately led to the adoption of a smaller clinical dataset and a simplified consent model, which seemed to allay the concerns of both sectors. Once the summary care record programme was well-established, other requirements were considered and the summary care record clinical content was extended to support patients with chronic conditions seeking treatment across healthcare settings.

The English summary care record implementation was a top-down model, which was considered to be problematic in itself and the centralised model is likely to have introduced major challenges—though any implementation on such a scale would have inherent challenges. Connecting for Health was bound by large-scale, expensive contracts with major IT suppliers, and even small changes to facilitate the programme proved costly.<sup>(9)</sup> Following the identification of challenges with, and subsequent simplification of, the consent model, adoption rose from 50% to 80%.<sup>(4)</sup> The lessons that the programme leadership felt were learned in the later years of the programme included:

- Ensure that the critical mass of patients—at least 50%—in a given cohort have summary care records available before rollout. Otherwise healthcare professionals have too many unsuccessful requests for summary care records and abandon the system.
- Start with the (full) enriched data set, not the core dataset—uptake of the core data set was good initially, but slow when the enriched data set was introduced subsequently.

- Use APIs to retrieve the record dynamically from where they're stored, don't store the summaries centrally.
- Ensure that it is clear if the patient has opted out.

As the summary care record programme matured, these challenges were addressed and adoption increased.

## Chapter 3 Norway

The Norwegian summary care record containing a summary of the citizen's core health information—that is, information that could affect medical treatment administered to the patient, especially in emergency situations. The record includes recent admissions, dispensed medications, and alert information—such as allergic reactions and critical medical conditions—and is created automatically for all 5.3 million citizens, who retain the option to opt out. To date, about 5000 persons (0.1% of the population) have opted out.

By the early 2000s, many Norwegian hospitals and all GPs had an electronic medical record, and could share discharge summaries and eReferrals, but not electronic medical record data—in emergency situations, there was no patient history. Initially identified as a key strategic programme in 2008, the preliminary summary care record project was conducted in 2010. Included in the national budget for 2012, rollout of the National summary care record began the following year in several locations, a few months before legal authority was granted through a change to the Health Register Act. A public information campaign began and initial rollout began in several locations. By 2015 the summary care record had been rolled out nationally.

SCR information is sourced automatically from a number of existing registries:

- Demographics registries
- Health personnel registries
- National ePrescriptions database
- National registry of specialist admissions

### 3.1 Governance

The Norwegian Ministry of Health and Care Services sets national policy, while the subordinate Norwegian Directorate of Health is responsible for implementation of this policy.<sup>(43)</sup> The Norwegian Board of Health Supervision is responsible for supervision of health services in Norway.<sup>(43)</sup> The Norwegian summary care record programme required changes to the Norwegian Health Act.<sup>(7)</sup> These changes were not in place when the programme began, but funding had been allocated and Parliament indicated clear expectations for the

deployment of the project, so programme management were comfortable initiating development of summary care records while waiting for the Health Act to change.<sup>(7)</sup> The legislation changes were made and, a few months later, the pilot went live.<sup>(7)</sup>

The Norwegian summary care record programme can be considered to be a 'middle out' implementation, where Government, industry, and clinicians collaborated to create national standards for interoperability and to encourage compliance.<sup>(5)</sup> This is considered to be the most effective approach to implementation.<sup>(5)</sup> For more information about the three types of national implementation, see the Types of implementation section on page 255.<sup>(5)</sup>

The National Standard defines the clinical content in the Norwegian summary care record.<sup>(7)</sup> A project working party and expert group worked to draft the national standard, informed by international models for critical information—in particular, by the Swedish National Patient Overview, the lead author of which participated in the working group.<sup>(44)</sup>

- Version 1.0 was tested as part of the pilot that took place from 2013 to 2014.<sup>(44)</sup>
- Version 2.0 was updated with feedback from version 1.0, following public consultation in 2015, and implemented as the national standard in the summary care record in 2016.<sup>(44)</sup>

'Reference groups' were convened during the pilot phase. These groups—consisting of healthcare professionals, patient representative organisations, administrative personal, and healthcare professionals organisations: organisations for doctors, nurses, and so on—met every month for the first few years for the project. All groups had equal weight and had access to the same documents and information. After the pilot stage, the groups were disbanded. A group of medical experts now advises on document sharing. Patient organisations are called upon if there is a specific need. But the document is considered primarily to be communication between healthcare professionals.

The Directorate for eHealth is responsible for the clinical data model and the processing of data. Patients and the responsible physician/hospital are responsible for the clinical content. Healthcare professionals access the summary care record from the patient's electronic medical record, using a high security log in.

Patients access their summary care record through the helsenorge.no page, using a secure log in. As a rule, a healthcare professional must have the patient's consent to access the



summary care record. But there are extensive exceptions to this rule—if there is an emergency and if the healthcare professional:

- Is the patient's general practitioner
- Is a nurse or a doctor in specialist healthcare
- Is employed in the emergency departments, an emergency call-centre or out of duty medical response-office
- Is employed in a nursing home or home care service with medical responsibilities

In all these cases, the patient privacy is established in other ways. Any time the summary care record is accessed, details are recorded in an access log that is available to the patient on the internet. The name and workplace of every healthcare professional that has accessed the summary care record is listed. Patients can subscribe to receive a warning by email if anyone opens their summary care record.

The patient can block access to the summary care record or parts of it. By activating this type of blocking the patient requires all healthcare professionals to actively consent to having a valid reason to attempt access. The consent screen is also shown to healthcare professionals who are not normally required to provide consent. The patient can ask for a warning if anyone bypasses the consent screen. Unauthorized access to the summary care record is a serious crime and healthcare professionals face legal actions if doing so.

The Norwegian summary care record provides many ways to control what is on the system without reverting to the complete opt out, which creates good will. Citizens can access several privacy features online (requires strong authentication):

- block named health personnel from accessing their summary care record,
- lock down part of their summary care record for all health personnel,
- put a soft block on all or parts of the summary care record for all health personnel,
- view access logs, to see who has accessed their summary care record,
- manage their notifications setting (about when people access their summary care record),
- make their own summary care record inaccessible from the internet,
- opt out, removing their own summary care record.

Citizens can make their own summary care record inaccessible from the internet, though it remains accessible to physicians through a closed private health network. This option is often used where there is a difficult relationship with a spouse.

The summary care record won a privacy award for the national data protection commissioner due to all the choices that were made available to patients. If a patient identifies an error, or they don't agree with the information present in the summary care record—for example, a visit or prescribing information—they can report it to the physician or to the eHealth Directorate, which will liaise with the healthcare professional who recorded the information and put a note on the section that the patient identified as incorrect.

## 3.2 Implementation

The pilot and national adoption project took three and a half years. The strategy consisted of a pilot phase to test the summary care record and methods of implementation, before the regional implementation phase, which was undertaken in cooperation with the four Regional Health Authorities.<sup>(7)</sup> Each Regional Health Authority consists of between 3 and 10 smaller regions or groups of hospitals.<sup>(7)</sup> 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.<sup>(7)</sup>

This staged implementation strategy can be summarised as follows:

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

### **Phase 1 – Small, well-controlled pilot (2013)**

*20 GP offices, 5 municipalities (community centres), 1 emergency call centre and 1 out-of-hours medical response office in central Norway*

In 2013, a small, well-controlled pilot was undertaken in one of the central regions in Norway.<sup>(7)</sup> As major stakeholders, the hospital director and the managers from the emergency units and municipalities formed a local steering groups, which ensured focus and ownership.<sup>(7)</sup> GPs were paid for the time spent registering patients' critical information, and

this helped establish the fee that GPs could charge subsequently.<sup>(7)</sup> All aspects of the pilot were evaluated thoroughly: content, usability, robustness, technical issues, training materials, and so on.<sup>(7)</sup> Early in the project, a set of measures to assess usage were defined and used to actively manage adoption.<sup>(7)</sup> Key learnings led to changes to the system and the implementation methods, while success stories were incorporated into the training.<sup>(7)</sup>

### **Phase 2 – One extended pilot for each Regional Health Authority (2015-6)**

Over 2015 and 2016, the initial pilot was extended to include one hospital in every region in Norway.<sup>(7)</sup> Each Regional Health Authority also undertook its own pilot, in one of the hospitals or hospital groups, to ensure that the implementation worked.<sup>(7)</sup> All hospitals, specialist healthcare units, and emergency units in the region or group were included in the pilot, as were all surrounding municipalities.<sup>(7)</sup> The Regional Health Authorities provided training and technical support to these organisations while the Directorate supported the general practitioners and primary care centres.<sup>(7)</sup> The Directorate led the public information campaign, generating and distributing e-mails, leaflets, posters, websites and media coverage, with the Regional Health Authorities supplementing through their own channels.<sup>(7)</sup> Reports on regional usage helped to create 'some energy/healthy competition'.<sup>(7)</sup> The evaluation report concluded that the national implementation was worthwhile.<sup>(7)</sup>

### **Phase 3 – Full national implementation (2016)**

Between 2016 and 2017 the programme was rolled out nationally.<sup>(7)</sup> Each Regional Health Authority was responsible for their rollout out within hospitals and had a plan for implementation. Regional Health Authorities typically adapted the pilot implementation as necessary for their region and set up local groups for individual hospitals.<sup>(7)</sup> Two Regional Health Authorities achieved implementation within a year, while the largest—covering approximately half of all hospitals—achieved implementation within 3 years.<sup>(7)</sup> The Directorate had responsibility for roll out within general practitioner and community settings.<sup>(7)</sup>

### **Phase 4 – Post implementation support**

In regions where usage was identified as low, the Directorate for eHealth deployed several resources for six months, to provide support through training and information.<sup>(7)</sup>

**Table 3 - Implementation of the Norwegian summary care record**

<b>Date</b>	<b>Event</b>
<b>2008</b>	<ul style="list-style-type: none"> <li>• Summary care record identified as a strategically important initiative.</li> </ul>
<b>2010-2011</b>	<ul style="list-style-type: none"> <li>• The Directorate of Health conducted a preliminary project, outlining the summary care record and how it could develop over time. Reference groups were used to evaluate content.</li> </ul>
<b>2011-2012</b>	<ul style="list-style-type: none"> <li>• The primary contractor was identified, through the procurement process. Accenture was chosen as the main cooperative partner.</li> </ul>
<b>2012*</b>	<ul style="list-style-type: none"> <li>• 85 million kroner (approx. €8.3 million) of the national budget was earmarked for the establishment of a national summary care record, with Parliament expecting the pilot to start in autumn 2013, a very tight production schedule.</li> <li>• Legal authority was granted for the establishment of the summary care record, resulting in a change to the Health Register Act.</li> <li>• Development of summary care record began, in parallel with regulatory measures.</li> </ul>
<b>2013</b>	<ul style="list-style-type: none"> <li>• Regulations for the Summary Care Journal were adopted.</li> <li>• An information campaign for the Norwegian citizens was launched.</li> <li>• Initial pilot launched to ensure the summary care record implementation worked.*</li> </ul>
<b>2014</b>	<ul style="list-style-type: none"> <li>• Separate project for ensuring national adoption (Stavanger region).</li> </ul>
<b>2015-6</b>	<ul style="list-style-type: none"> <li>• Extended pilots in each Regional Health Authority</li> </ul>
<b>2016-7</b>	<ul style="list-style-type: none"> <li>• National implementation of the summary care record</li> </ul>
<b>2017</b>	<ul style="list-style-type: none"> <li>• Summary care record had been rolled out to <ul style="list-style-type: none"> <li>○ all hospitals,</li> <li>○ all emergency call-centres,</li> <li>○ all out of duty medical response-offices,</li> <li>○ about 85% of general practitioners.</li> </ul> </li> </ul>

\* Initial roll-out in Trondheim, Malvik, Melhus og Klæbu in August 2013, with 21 healthcare professionals selected as pilot users. In November 2013, the pilot was rolled out to all healthcare professionals in the pilot area.

The extremely tight development timeline, with the launch of a pilot after only a year of development, made some architecture decisions necessary. For instance, it was decided to

implement a solution with a portal to access the summary care record within the user's electronic medical record. Therefore the changes that the electronic medical record vendors had to implement, was strictly limited.

**Table 4 - Norwegian summary care record clinical information and sources**

Section	Description	Source
<b>About the patient</b>	Name, address, family, civil status, name of the general practitioner (preceding 3 years)	National registry, National contact and reservation registry, General Practitioners registry
<b>Medications</b>	All medications that are dispensed by pharmacies, from both electronic and paper prescriptions (preceding 3 years)	Prescription Intermediary system. (Norwegian: "Reseptformidleren")
<b>Contact</b>	Family members (with telephone-numbers), address and name of the patient's GP	Various national registers
<b>Admissions</b>	Any admission to the specialist health service*	Norwegian Patient Registry
<b>Critical information</b>	<p>Important for healthcare personnel: information that may affect treatment decisions, especially in emergency situations:</p> <ul style="list-style-type: none"> <li>• Hypersensitivity reactions</li> <li>• Complications with anaesthesia</li> <li>• Critical medical conditions</li> <li>• Continuing treatments and implants</li> <li>• Changes to ordinary treatment routines</li> <li>• Contagion</li> </ul>	<p>GP enters, with patient's consent.</p> <p>Nurses and psychologists can update some elements.</p>
<b>Privacy settings</b>	<ul style="list-style-type: none"> <li>• Reservations</li> <li>• Patient consent poster</li> <li>• Blocking of named health personnel</li> <li>• Notifications profile</li> </ul>	The patient can update this section.
<b>Patient's own registrations</b>	<ul style="list-style-type: none"> <li>• Primary contact person</li> <li>• Disease history (structured selections)</li> <li>• Special needs—such as diminished sight or</li> </ul>	The patient can update this section.

- hearing, need for translator
- Organ donation information

\*Diagnoses are not displayed.

Each summary care record content section has a light blue icon, except the critical information section, which has a red icon. The icon is greyed out if the patient has opted out of the section.

Some sections populated automatically from the corresponding national registries.

**Table 5 - Norwegian national registries**

Register name	Description of information
<b>National registry</b>	Name, birth day, national identity number, address, marital status, family details
<b>National contact and reservation registry</b>	Cell phone number, email (patient, family members)
<b>Register for Health Personnel</b>	Not available
<b>RGP-register*</b>	Patient's regular GP (name, address, phone)
<b>National Database of e-Prescriptions</b>	Three year history of e-prescriptions and pharmacy-dispensed paper prescriptions
<b>Norwegian Patient Registry</b>	Admission history to specialist health service since 2008

\*Patients can be registered with only one GP in Norway, but can change GP.

The **Medications** section is populated in real-time from the National "Prescription Intermediary" system, which tracks all medications that have been dispensed at Norwegian pharmacies from prescriptions, written and electronic, in the last three years. Diagnoses are recorded for all prescriptions, from which they can be accessed. Not all diagnoses are held in structured format. Therefore, a list of approximately 200 critical diagnoses is maintained dynamically in structured format (ICD-10), with each specialist group reporting the diagnoses they would like included. They are currently working to move the ICD-10 codes and other internal codes to SNOMED CT.

Other sections of the summary care record are updated manually:

- Critical information** provides important information for healthcare personnel—information that may affect treatment decisions, especially in emergency situations. This section is usually updated by the patient's GP, with the patient's consent. Multiple physicians can contribute to the record—for example, the GP and the emergency doctor—while a complete record is kept of who enter or updates the information. The critical diagnosis care (critical information is) recorded by attending physicians.

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- **Privacy settings** where, for example, patients can block healthcare professionals from viewing areas of the patient's summary care record.
- **Patient's own registrations** where patients can add critical information. For example, the patient can list their primary contact person. They can add information about special needs, such as difficulty with hearing or seeing. Patients can also ask a healthcare professional to help them to enter information.

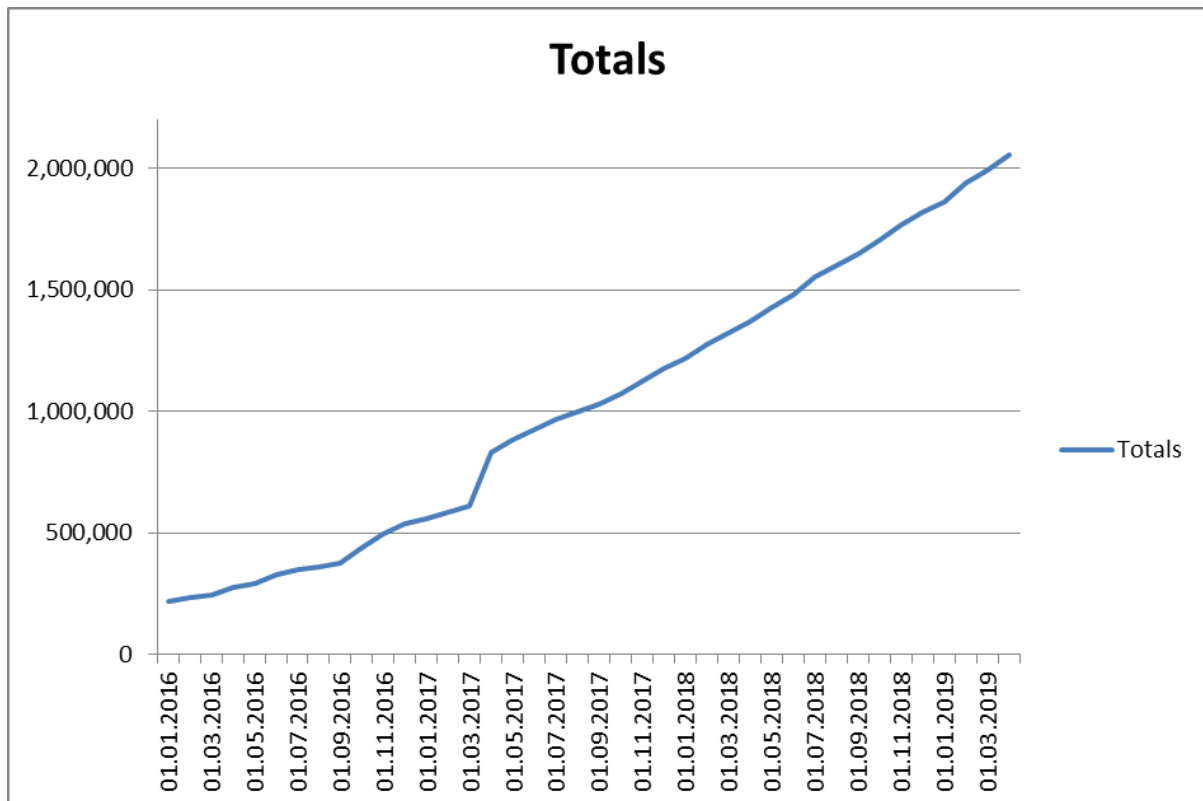
The summary care record will be extended to include an overview of clinical documents available in all Norwegian hospitals—discharge summaries, x-ray results and laboratory results. In March 2020, the summary care record was introduced into nursing homes and home healthcare in two municipalities. It is expected to be introduced into 30 more municipalities by the end of 2020.



### 3.3 Lessons learned

Since the Norwegian summary care record was launched at the beginning of 2016, approximately 2 million 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:

**Table 6 - Adoption rate of Norwegian summary care record**



An academic study of the Norwegian summary care record programmes showed that doctors working in emergency departments found summary care records particularly beneficial for three specific groups of patients: 1) unconscious patients, particularly where no information was held on file for them, 2) patients using multiple pharmaceutical products, and 3) patients with a history of substance abuse.<sup>(6)</sup> This finding was reflected in the results of a study on the Scottish emergency care summary.<sup>(6)</sup>

The doctors studied had high regard for the information in the pharmaceutical summary because it was automatically generated from the national pharmaceutical database daily.<sup>(6)</sup> In contrast, the critical information section must be updated manually on an on-going basis.<sup>(6)</sup> While GPs typically updated summary care records regularly, hospital doctors did

not—and therefore expected that their hospital doctor colleagues did not either, leading them to trust in the manually-updated content of the summary care record far less.<sup>(6)</sup> Thus, three years after implementation, the doctors studied checked whether the icon was red, to indicate alert or critical information, but did not rely on the colour coding, often suspecting the icon to be blue because no one had entered the critical information, rather than because there was no critical information.<sup>(6)</sup>

The current implementation means that doctors must put their security credentials in twice—after logging in to their system, they click a button to launch the summary care record system, but have to put in their security credentials again. The recommendation given was to start implementing interfaces early, with a view to ensuring better integration with vendors systems.

Finally, leadership in the Norwegian implementation recognised that citizens had become far more aware of data sharing and rules around consent. Therefore, it was considered very important that patients understood that they could opt out of having a summary care record.

## Chapter 4 Scotland

The Scottish emergency care summary was a clinically-led programme to introduce a basic summary care record, initially listing the patient's medications and allergies.<sup>(3,8)</sup> The allotted budget was £0.5 million and the emphasis was on maximum reuse of the existing infrastructure.<sup>(9)</sup> The pilot took place in two Scottish health boards in 2004, and in 2006 the emergency care summary was rolled out nationally.<sup>(3)</sup> By 2011, over 99.9% of Scotland's 5 million citizens had an emergency care summary, the first summary care record programme to achieve national coverage.<sup>(8)</sup>

Prior to the emergency care summary implementation, all Scottish GP practices already used a standard configuration, with information about medications and allergies relatively well structured.<sup>(3)</sup> Existing electronic links with GP practices were used to connect to a new national data store, built specifically to store the records.<sup>(3)</sup> The Community Health Index, a population register (database) used for healthcare purposes, was also considered to be a prerequisite.<sup>(10)</sup> Patients' medical and demographic details were, and continue to be, uploaded twice daily from GP records.<sup>(3)</sup> Separate legislation was not needed for the Scottish emergency care summary.<sup>(11)</sup>

Introduced in 2013, the Scottish Key Information summary extended the clinical dataset, providing the requisite information for patients with long-term conditions, mental health problems, additions, or terminal conditions to be treated during episodes of unscheduled care.<sup>(45)</sup>

**Table 7 - Implementation of the Scottish Emergency Care Summary**

Date	Event
<b>2004</b>	Pilot project for Scottish emergency care summary in two health boards.
<b>2006</b>	National rollout of the Scottish emergency care summary.
<b>2011</b>	Over 99% of 5 million citizens had a Scottish emergency care summary.
<b>2013</b>	Key Information summary implemented.

## 4.1 Governance

The Scottish Government Health and Social Care Directorate is responsible for the development and implementation of health and social care policy.<sup>(46)</sup> It allocates funds to and sets strategic direction for National Health Service (NHS) Scotland.<sup>(46)</sup> NHS Scotland is divided into 14 regional NHS boards, seven Special NHS Boards and one public health body.<sup>(47)</sup> Regional NHS Boards are responsible for public health in their areas, while Special NHS Boards provide a range of specialist and national services.<sup>(47)</sup> In February 2007, NHS Scotland published a framework for handling information in a confidential and secure manner in accordance with ethical and quality standards.<sup>(48)</sup>

The Scottish emergency care summary programme had two major governance groups:<sup>(11)</sup>

- **Emergency Care Summary Programme Board**, chaired by a lead or senior GP, was responsible for all aspects of the programme including the business case and the implementation of the system. Patient groups were also represented, as was clinical leadership—which was considered key for the clinical buy-in necessary for overall success. The Board governed the pilot in one Health Board.
- **Emergency Care Summary Service Board**, was responsible for the day to day operational management of the system.

An information commissioner chaired a working group to agree the correct process for obtaining patient consent. The board was closed in 2014 once the key information summary had been delivered. The emergency care summary Programme Board reported into an overarching eHealth governance body within Scottish Government and having the link in place was also crucial to ensuring support for the programme.

The Scottish emergency care summary programme was clinically led from the beginning—the first year of the emergency care summary programme was dedicated entirely to building consensus within clinical groups around format and clinical content, with the Scottish Consumer Council also undertaking a series of focus groups.<sup>(3)</sup> The General Medical Council, the Information Commission and professional societies worked together closely, to agree each stage of the work programme.<sup>(3)</sup> New developments, which originated within the clinical community, had strong support from the Scottish General Practitioners' Committee of the British Medical Association.<sup>(3)</sup>

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As such, the Scottish implementation can be considered to be a middle out implementation, the most effective and successful of the three models—described in Types of implementation on page 255. In a middle out national implementation, Government, industry, and clinicians collaborated to create national standards for interoperability and to encourage compliance.<sup>(5)</sup> Government facilitates a collaborative approach to implementation, including ensuring communicating effectively with the general public regarding the implementation.

A large, and quite expensive, part of the Scottish launch was a patient leaflet campaign in every house. The Scottish emergency care summary programme started with a very small summary—medicines, allergies—that proved very easy to explain to patients. The vast majority of citizens were in favour and the programme was well supported from the beginning.

As noted earlier, separate legislation was not needed for the Scottish emergency care summary.<sup>(11)</sup> The patient's permission to access the summary must be obtained during the consultation. Originally, this permission to access was requested by each treating healthcare professional. This surprised patients, who saw the National Health Service as a whole and considered they had given consent during the first consultation.<sup>(11)</sup> As time went on, this request for consent at each consultation was seen as a barrier.

A British Medical Association subcommittee engaged various citizens groups in a review process. It proved most efficient to ask for patient permission to view, which was provided consent in advance—for example, when the patient first rings the Scottish National Health Service 24-hour helpline, NHS24. A process was devised for situations where the patient was unable to give consent. All emergency accesses are audited and reviewed separately by the Health Board. Very clear guidelines are also in place—for example, about any unusual activity to be flagged. Part of the process is to reconcile all phone calls and visits to out-of-hours clinic or emergency department with views of audit logs—for example, if the patient's summary has been viewed but there is no record of phone call or of the out-of-hours clinic or emergency department visit, this needs to be investigated.

There are approximately 10,000 opt-outs from a population of around 5 million. Where a patient has opted out, the record is not uploaded. Instead, the patient's name and 'kai'

number are uploaded, together with the message—“This patient has opted out.” If the patient changes their mind, the summary can be uploaded to overwrite this file. The audit trail always shows all these actions.

Patients were broadly supporting but expressed concerns around opting out of the summary as well as who would have access to the summary and where it would be held. To ensure these concerns were properly addressed ahead of the implementation, the opt-out process was made easier and 12 to 18 months were allowed for feedback and approvals. Another leaflet campaign, directed at patients, provided clarity around the process.

Groups representing patients with sensitive and complex conditions were also engaged. For example, groups representing patients with human immunodeficiency viruses (HIV) indicated that the condition should not be listed explicitly but that, through the listing of HIV treatment medications, clinicians would understand immediately the nature of the patient’s condition.

Much emphasis had always been placed on consent, so there was little or no impact from the introduction of EU General Data Protection Regulation. The Information Commissioner Office was engaged, which (though not taking part in the formal governance structure) provided the advice.

## 4.2 Implementation

Initially, the Scottish emergency care summary, which is the name of the Scottish summary care record, listed the patient’s medications and allergies.<sup>(3)</sup> All Scottish GP practices use a standard configuration, with information about medications and allergies relatively well structured.<sup>(3)</sup> Existing electronic links with GP practices were used to connect to a new national data store, built specifically to store the records.<sup>(3)</sup> Patients’ medical and demographic details were uploaded twice daily from GP records.<sup>(3)</sup>

The Scottish programme benefitted from the part-ownership, by the Scottish Government, of one of the major system suppliers.<sup>(9)</sup> This system was deployed in 80% of Scottish GP practices, as the Scottish Enhanced Functionality.<sup>(9)</sup> As a result, development progress rapidly and other suppliers needed to conform to the Scottish Enhanced Functionality.<sup>(9)</sup> The programme was also marked by a spirit of cooperation between medical representative

organisations, patient groups, and the programme, particularly after the new GP contract devolved responsibility for out-of-hours care away from individual GP practices and to Health Board.<sup>(9)</sup>

The initial solution worked off individual servers in practices, with the GP creating or updating the record, triggering the change to go into the holding area. Changes were then uploaded as a batch feed from the practice. For large practices, the batch job might run 4-5 times per day. For smaller practices, the batch job might run once after the practice closed, often around 6-7pm. At that time, the length of time needed to upload the data created challenges. Currently, an API and databases shortens this time considerably.

The emergency care summary was built into users' systems, using Web services, so that it is displayed as part of the existing systems—much easier than having to log in separately. Web services were also used to make the emergency care summary available in the ambulance service tablets, though initially there were a lot of performance issues. A new unique identifier programme is also underway, as the current identifiers are in use for 30 years.

The emergency care summary pilot took place in two Scottish health boards in 2004, and in 2006 the emergency care summary was rolled out nationally.<sup>(3)</sup> During the initial rollout the updated software package was installed on the GP's server, local out-of-hours hospital server and emergency department server— with all these locations going live at the same time. The timing of the implementation was led by the readiness of the GP practices. Sometimes receiving connectivity was already in place on their end, making it relatively easy. Usually, the implementation of the emergency care summary was part of an upgrade.

The National Health Service 24-hour helpline, NHS24, proved harder to update—but this update coincided with a major upgrade. The recommendation was to avoid the 'big bang' approach. There are about 1,000 GP practices nationally and communications were targeted nationally. By 2011, all general practices in Scotland were connected.<sup>(3)</sup>

Cross border access is also being introduced, meaning that the emergency care summary is being made available to other health regions within Scotland. In general, 80-90% of patients access their local GP, emergency department and out-of-hours services. For example, in the

summer months, problems often occur when patients on holidays in other regions cannot access their emergency care summary—for example, in the Highlands, as many as 40% of the patients that attend GPs, emergency departments, or out-of-hours clinics are from outside the Highlands region. The national emergency care summary was introduced to allow sharing of the emergency care summary across health service regions within Scotland.

The Key Information Summary proved more challenging. The technical solution was to populate an XML extract to a holding database in the GP practice, which was sent over one central emergency care summary database in a national database. Initially there were real constraints over bandwidth and challenges with rural connectivity. Attachments also presented challenges, as it was not possible to guarantee the version number of the attachment. By 2013, the palliative care summary was fully rolled out—approx. 1.5 million patients have a Key Information Summary.

The decision was taken not to establish an online patient portal initially, for various reasons such as access rights around family relationships—for example, in the case of marriage or relationship breakdown. Instead, patients are required to go to the GP practice to view or update their details. Feedback can also be sent from the out-of-hours clinic or emergency department. Development of a patient portal is now being considered. The first step is to extend the Key Information System with a 'respect' form.

### 4.3 Lessons learned

An academic evaluation of the emergency care summary programme identified key features.<sup>(9)</sup> In contrast with the English implementation, the programme was clinically led from the beginning.<sup>(9)</sup> The emphasis was on maximising use of existing systems, as well as simplicity, fitness for purpose, and a restrained approach.<sup>(9)</sup> The use case—emergency care only—was tightly controlled and requirements were defined with a view to 'getting everyone on board'.<sup>(9)</sup> The programme was led by a small number of enthusiastic clinicians, and the programme engaged patients early in consultation.<sup>(9)</sup> The overall narrative was of 'improving clinical care and assuring quality and safety'.<sup>(9)</sup>

The implementation was seen as a partnership with stakeholders and progress made a rate that was comfortable for stakeholders.<sup>(9)</sup> The programme took a pragmatic approach to the trade-off between privacy and consent against access to data.<sup>(9)</sup> Clinicians led the public



information campaigns and were seen as the central drivers for clinical engagement.<sup>(9)</sup> Success was measured through clinical success stories and critical incidents, together with pragmatic audits to give an overview of key indicators.<sup>(9)</sup> The emergency care summary quickly became part of 'business as usual'. 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.<sup>(9)</sup> In a survey of 118 clinicians (as NHS24 users), 34% said it had changed a clinical decision.<sup>(9)</sup>

The expert recommendation is to show either all data or none—not to attempt to restrict views of part of the data, as this is highly complex both technically and in other ways. Patients actually seemed reassured by the sharing of information across the NHS.

The landing page of the emergency care summary initially contained a warning to healthcare professionals that the medications list may not include medications that were prescribed in hospitals, drug clinics, or mental health clinics, nor any prescribed on handwritten prescriptions.<sup>(9)</sup> This ensured that clinicians understood the completeness of the medications list in the record.

The lessons learned include:

- Keep the consent process as simple as possible.
- Minimise the impact on GPs.
- Ensure that the emergency care summary content can be retrieved and read in less than 30 seconds. otherwise the system is not practical for emergency services, ambulance services, and so on.
- Public information campaign around consent and data sharing formed a huge part of their launch, including leaflets to every house.
- Share either all the data or none. Restricting access to part of the data is too challenging, technically and in other ways.
- Do not allow attachments to emergency care summaries.

The overall conclusion was that introducing the emergency care summary was 'definitely the right thing to do'.

## Chapter 5 Northern Ireland

Serving a population of 1.5 million, Northern Ireland is a small, geographically contained area with 5 GP out-of-hours centres and 11 emergency departments.<sup>(3)</sup> The Northern Ireland emergency care summary programme adapted the Scottish summary care record, as well as the overall Scottish approach to implementation. Similar to the Scottish implementation, the emergency care summary programme was initiated collaboratively and was clinically led.<sup>(9)</sup> A small clinical dataset was defined—demographic details, medications, and allergies.<sup>(3)</sup>

The Health and Care number, a unique health identifier for all healthcare services, was already in use before the emergency care summary was implemented and the quality of the demographic information in GP practice management systems was high.<sup>(3)</sup> While an electronic prescribing service has not been implemented, prescriptions contain barcodes with information that can be read and uploaded at any community pharmacy. Once the Northern Ireland electronic care record, a more comprehensive shared care record, was introduced, the Northern Ireland emergency care summary was integrated to feed into it.

**Table 8 - Implementation of the Northern Ireland Emergency Care Summary**

Date	Event
2008	Pilot project for Northern Ireland Emergency Care Summary in one National Health Service Trust.
2010	National rollout, recommended by Regulatory and Quality Improvement Authority.
2013	Data being extracted daily from 365 GP practices.

### 5.1 Governance

Northern Ireland Health and Social Care, the National Health Service organisation for Northern Ireland, is responsible for implementing policy defined by the Department of Health.<sup>(49)</sup> The Health and Social Care organisation is comprised of several Northern-Ireland-wide bodies, such as the Northern Ireland Ambulance Trust and five regional trusts.<sup>(49)</sup> The regional trusts provide and manage a wide range of health and social care services in their communities, including primary care.<sup>(49,50)</sup> The Regulation and Quality Improvement Authority (RQIA) regulates the delivery of these services.<sup>(51)</sup>

The Data Protection Act 1998 provided the eight fundamental principles for the use of personal data, including healthcare data.<sup>(52)</sup> Health and Social Care's Standard on Information and Communications Technology also requires providers to use a consistent, comprehensive and systematic approach to managing electronic information and systems.<sup>(48)</sup> All health and social care providers must adhere to the Code of Practice on protecting the confidentiality of service user information, which the Department of Health published to ensure that the privacy and confidentiality of individuals are safeguarded.<sup>(48)</sup>

At the beginning of programme implementation, the Northern Irish emergency care summary Project Board was established.<sup>(12)</sup> The Board had representation from the professional body representing general practitioners, the Department of Health, the IT community, directors of some healthcare trusts, and representatives of the Health and Social Care Board.<sup>(12)</sup> Thus, the Northern Ireland emergency care summary programme can be considered a 'middle-out' implementation, where Government, industry, and clinicians collaborate to create national standards for interoperability and to encourage compliance—this is defined further in the Types of implementation on page 255.<sup>(12)</sup> A 'middle-out' implementation is considered to be the most effective and successful of the three implementation approaches.<sup>(12)</sup> Different workstreams were established, including engagement with suppliers.<sup>(12)</sup>

## 5.2 Implementation

Similar to the Scottish programme, pragmatic decisions were made to adapt and build on existing systems and infrastructure, rather than a centrally driven, State-led effort to create an overarching infrastructure, as was attempted in England.<sup>(9)</sup> Independent evaluations attributed the programme's success largely to the strong and consistent engagement of clinicians' support.<sup>(3)</sup>

For the pilot project, testing ran in one National Health Service trust in 2008, with close liaison with the Scottish group.<sup>(3)</sup> The pilot project consisted of one out-of-hours clinic and about 50 GP practices. The emergency care summary was well established within a year. The pilot identified issues with data quality and governance, as well as some technical issues, which were all resolved. Following a recommendation by the Regulatory and Quality Improvement Authority of Northern Ireland, national rollout began in 2010.<sup>(3)</sup> By 2013, data

was being extracted daily from the 365 GP practices, with the emergency care summary available to the out-of-hours centres, emergency departments, and hospital pharmacy departments, with extension of the scheme to other areas, such as the Ambulance service, being considered.<sup>(3)</sup>

The Health and Care number facilitated the exchange of information between health services through the Health and Care Index and as far as possible, the emergency care summary took information from the Health and Care Index and made updates to the Master Patient Index available through it.<sup>(12)</sup> Many systems receive information from the Health and Care Index.<sup>(12)</sup>

The Northern Ireland emergency care summary was managed initially by the company, ATOS, for the first few years of the programme.<sup>(12)</sup> Once the Northern Ireland electronic care record was implemented, the ATOS system was switched off.<sup>(12)</sup> The Northern Ireland electronic care record requirements included the emergency use case, which the emergency care summary covers, as well as the patient's general health information.<sup>(12)</sup> The patient's GP can see their Northern Ireland electronic care record.<sup>(12)</sup>

Emergency care summary information is transferred nightly from the GP practice management system to the Northern Ireland electronic care record.<sup>(12)</sup> If the patient moves to a new GP practice, their emergency care summary moves with them—but their prescription record is not transferred. Healthcare professionals access the emergency care summary through the patient's Northern Ireland electronic care record using their username and password.

Each patient in a GP practice has a Health and Care Number, which can be used to retrieve their record. Healthcare professionals are usually assumed to have legitimate reasons for accessing the patient's emergency Care summary, if they have the patient's Health and Care number. However, a full time auditor takes daily sample from the emergency care summary and compares against it to the record of attendance at out-of-hours clinics for legitimate accesses.

### 5.3 Stakeholder Engagement

Stakeholder engagement was considered to be a key workstream and prerequisite, including many face-to-face meetings with patients and focus groups.<sup>(12)</sup> Clinical champions drove the project, with one GP in the out-of-hours clinic putting considerable energy into driving the pilot project. Local patient groups were also involved in pilot groups.

The Northern Ireland Patient and Client Council, a body with an established group of patients, was also engaged.<sup>(12)</sup> A campaign was launched in 2004, with leaflets dropped to every household, as well as radio and newspaper ads.<sup>(12)</sup> The campaign explained the opt out mechanism—the wording of each was considered very carefully—and about 100 people opted out.<sup>(12)</sup> The majority of systems are now electronic, and those who have opted out will be informed that it is no longer practical to facilitate those who have opted out.<sup>(12)</sup>

Initially, the campaign committed to using the data collected for the Northern Ireland emergency care summary for direct healthcare only.<sup>(12)</sup> This built public confidence, which created a favourable environment for the expansion of content, as part of emergency care summary extra and for requesting patients' permission to use emergency care summary data for secondary use.<sup>(12)</sup> The communications group was clinically led, with patient representation.<sup>(9)</sup> Success was measured through clinical success stories and critical incidents, together with pragmatic audits to give an overview of key indicators.<sup>(9)</sup>

### 5.4 Lessons learned

The Northern Ireland emergency care summary was considered useful both to address the unscheduled care use case, 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 not the surreptitious introduction of an electronic health record. This built public confidence in the programme.

Programme leadership also highlighted the need to monitor the quality of emergency care summary data. Initially, the GP practice data is uploaded to the emergency care summary, changes are then uploaded nightly. The emergency care summary team checks daily whether uploads from practices have failed—for example, if the GP practice has not kept pace with changes—or if a practice has stopped submitting records. In these cases, the record may need to be rebuilt.

## Chapter 6 Other countries

In Estonia and Spain, the patient summary use case is addressed through the existing electronic healthcare records systems. Patient summaries are under consideration but have not yet been implemented in Austria, Finland, and Denmark. This chapter highlights examples of relevant best practice from each of these national implementations.

### 6.1 Estonia

All healthcare providers are legally obliged to supply documents to the Estonian National Health Information System (ENHIS). This national central electronic database processes the health records of all patients receiving healthcare services from any Estonian healthcare service provider.<sup>(13)</sup> Key clinical information from the database is made available through the Time Critical Data, to support healthcare professionals treating patients during episodes of unscheduled care.<sup>(13)</sup> The same identifier is used for each citizen across all eGovernment Services.<sup>(13)</sup> Patients can view all of their data stored on the ENHIS on the patient platform 'My E-Health'. All Estonian e-health services use the national infrastructure, X-Road. Other eHealth services in place include an ePrescribing service, and a GP portal.

#### 6.1.1 Governance

The Estonian Ministry of Social Affairs has responsibility for health policy and strategy. The Estonian eHealth Foundation was established in 2005 by the Ministry, together with the major hospitals, and trade associations of healthcare professionals, to coordinate Estonian eGovernment services. The Foundation manages the Estonian national health information system. The national Data Protection Inspectorate supervises whether health data, including electronic health records are processed in compliance with sensitive personal data protection rules.

Estonia began the digitization of government services shortly after it achieved independence in 1991, laying the foundations of the legislative framework for electronic services. In 2002, legislation was passed specifically to enable the exchange of health data, equalising digital and paper records.<sup>(13)</sup>

The State infrastructure for data exchange, named X-Road, used for all eGovernment Services including eHealth services, was established in 2004. The authentication services uses a block chain log for access audit, stored centrally rather than distributed.<sup>(13)</sup> And in 2007, legislation introduced key components for healthcare, such as strong authentication, obligations to send data, and patients' rights.<sup>(13)</sup> By law, all organisations creating new data have to make the data open for sharing.<sup>(13)</sup>

Established in 2008, the Estonian national health information system (ENHIS) is the national central electronic database for processing health data of all patients receiving healthcare services from any Estonian healthcare service provider. By law, all officially recognised healthcare service providers must upload their patients' EHRs to ENHIS.

Patients can view all of their data stored on the ENHIS on the patient platform 'My E-Health'.

In every sector, the citizen is considered to be the owner of the data and always has the right to see who has viewed their data.<sup>(13)</sup> By law, citizens can opt-out of having their data uploaded.<sup>(13)</sup> They can also close down access to one or all of their documents.<sup>(13)</sup> However, in the last 10 years, this option has been used about 500 times—from 48 million documents for 1.4 million people.<sup>(13)</sup> Citizens can monitor access logs, to see who has accessed their data.<sup>(13)</sup> Patients have the right to view 100% of their data in the central repository through the patient portal, including their time critical data.<sup>(13)</sup>

The Estonian eHealth Foundation agrees the standards, which third parties such as the vendors must accommodate, encourage the adoption of uniform terminology.<sup>(13)</sup> Governance structures for the Time Critical Data Service included representatives from emergency care, such as members of the ambulance services, and emergency anaesthetists, doctors, nurses and others.<sup>(13)</sup>

### **6.1.2 Implementation**

As noted earlier, all healthcare providers are legally obliged to supply documents to the Estonian national health information system (ENHIS) database, which processes the health records of all patients receiving healthcare services from any Estonian healthcare service provider.<sup>(13)</sup> Standardized data items are taken from the documents and stored in the central repository for integration and legal purposes, then services are built using these data items.<sup>(13)</sup> They consider that they are not using the full potential of their data.<sup>(13)</sup>



**Table 9 - Implementation of the Estonian Time Critical Data Service**

Date	Event
2002	Legislation for Government electronic services (eServices)
2005	Estonian eHealth Foundation established. eHealth projects (EHRs) begun
2007	Legislation introduced key components for healthcare
2008	(December) Estonian EHR launched, with nationwide information campaign
2009	Patient portal launched. GPs and hospitals connected to X-road infrastructure
2010	Prescription centre connected to X-road infrastructure
2013	Revised patient portal and GP portal launched.
2016	<i>Time Critical Data</i> service established, for episodes of unscheduled care

The Time Critical Data service makes a standard dataset of key clinical information, sourced from the central information repository, available to healthcare professionals treating patients during episodes emergency care. For example, ambulance staff can request time critical data on a mobile device using the patient's unique national identifier.<sup>(13)</sup> Examples of time critical data include hospitalizations, major events, medications, and allergies.<sup>(13)</sup>

At the time of writing, GPs also had to consult several documents to retrieve clinical information required to treat their patients. A new service, named the patient summary, will source that clinical dataset from the national database and make it available to the GP in one place.<sup>(13)</sup> There are plans to develop a data viewer, which would provide a longitudinal view of the data history for five years.<sup>(13)</sup>

The central database has reached the maximum permitted age for Estonian infrastructure components. A move to 'Health Information Exchange 2.0' is also planned, to move the system to event-based, rather than document-based, data exchange.<sup>(13)</sup> Document-based exchange presents challenges—for example, a discharge summary document could remain open until lab results arrive, days after the discharge date.<sup>(13)</sup> If the patient leaves the hospital, the ambulance should know that they've been discharged.<sup>(13)</sup> The intent is to create more dynamic, smarter services from smaller items, such as the time critical data items,

within a service-oriented architecture.<sup>(13)</sup> So, rather than sending a single discharge summary for an episode in hospital, event-based information would be sent instead.<sup>(13)</sup>

### 6.1.3 Stakeholder engagement

Document sharing for patient discharge and ambulance services was introduced first, with electronic referrals, ePrescribing, and school notices following.<sup>(13)</sup> Implementations were introduced step by step, sector by sector.<sup>(13)</sup> User groups for each document type were already involved in standardisations.<sup>(13)</sup> Implementations start with the clinical need of users, and healthcare professionals, such as midwives, GPs, and nurses, were invited.<sup>(13)</sup> Once problematic content was agreed, technical standardisation could progress and was outsourced to companies.<sup>(13)</sup> Governance structures for the Time Critical Data service included representatives from emergency care, such as members of the ambulance services, emergency anaesthetists, doctors, nurses, and others.<sup>(13)</sup> Patients were not involved in these structures as the service is considered to provide communication between healthcare professionals.<sup>(13)</sup>

### 6.1.4 Lessons learned

The Estonian Electronic Health Record and central repository of health data have been in operation since 2008, when the legislative framework and infrastructure for Government eServices were already well-established. An electronic prescribing service, a national patient portal, and other key eHealth systems were established subsequently. These systems facilitated the introduction of the Time Critical Data service, which provides key clinical information to healthcare professionals during episodes of unscheduled care.

## 6.2 Spain

The Spanish Health system is devolved into 17 Autonomous Regions, with the State Ministry for Health mainly responsible for coordinating between these Regions.<sup>(14)</sup> The Ministry is also responsible for generating a unique health identifier for each Spanish citizen, stored together with basic demographic information in a database that is used by the 17 Regions.<sup>(14)</sup> This personal identification code is usually carried on an e-card. Each Region assigns a specific identifier to the resident, which helps ensure interoperability between the Regions. Other national standards have also been defined—for example, the minimum content for the clinical history to be used in all regional health systems was defined in law,

though not necessarily in electronic format, to ensure the continuity of care nationally. This ensures the interoperability of systems across the Autonomous Regions, which is seen as essential to the efficiency of the system.

In the Autonomous Region of Andalucía, a full electronic health record named DIRAYA is available everywhere on the public health network. Each Andalusian citizen is assigned two health identifiers: a unique national health identifier, assigned and managed by the Spanish federal government, and a linked region-specific identifier, assigned and managed by the Andalusian Health Service. These identifiers ensure the security of DIRAYA. The landing page of the patient's DIRAYA record summarises the patient's key clinical information—such as, health conditions, allergies, prescriptions, and contact information within the healthcare system—in compliance with the Spanish national standard.<sup>(53)</sup> This corresponds to the use case defined by the Irish National Standard on Information Requirements for a National, Electronic Patient Summary, for episodes of unscheduled care.

### 6.2.1 Governance

As noted earlier, the Spanish Health system is devolved into 17 Autonomous Regions, with the State mainly responsible for coordinating between these Regions.<sup>(14)</sup> Governed by the Junta de Andalucía, the Autonomous Region of Andalucía has a population of over 8 million—about 18% of the Spanish population.<sup>(15)</sup> The Servicio Andaluz de Salud (SAS, Andalusian Health Service) is responsible for public healthcare provision on behalf of the regional Ministry of Health and the Junta de Andalucía. SAS deploys an infrastructure of:<sup>(15)</sup>

- 1500 primary healthcare centres (PHC)
- 28 hospital areas.

There are 3,584 private pharmacies.<sup>(15)</sup> All providers—GPs, pharmacists, hospital doctors—are salaried civil servants, with some small private hospitals as exceptions.<sup>(16)</sup>

Spanish legislation on health data is based on the assumption of implicit consent for healthcare and health service providers are subjects to regulation on the medical data that must be maintained for each patient. Under national (Spanish) agreement, citizens are considered to own the data and the health service provider considered to be the keeper of the data.

## 6.2.2 Implementation

The Andalusian Health Service began to implement a full electronic health record system, DIRAYA, began approximately 20 years ago for the population of approximately 8 million citizens. The ultimate aim of DIRAYA was a single electronic health record system shared by all healthcare providers, with the initial focus on primary care.<sup>(15,16)</sup>

DIRAYA used existing infrastructure and processes, with new components being developed as required. In the mid-1990s, the national Ministry of Labour and Social Security (MoL) and its regional counterpart Ministry developed a system to administering sick leave from work—La Tarjeta de Afiliado a la Seguridad Social (TASS)—in real time.<sup>(15)</sup> Each primary healthcare centre had its own TASS database on its own local service.<sup>(15)</sup> In 1998, SAS decided to integrate over 1000 PHCs, and planning and development for DIRAYA began.<sup>(15)</sup>

The first step in developing DIRAYA was developing the Citizen Register.<sup>(15)</sup> Since 2001, it generates the Numero Unico de Historia de Salud in Andalucía (NUHSA) for each citizen, linking all the citizen's health record.<sup>(15)</sup> NUHSA is generated at birth or on first contact with the SAS services, which is held on the citizen's smart card.<sup>(15)</sup> In 2009, 98% of residents had NUHSAs.<sup>(15)</sup>

The critical components of DIRAYA were:

- **Citizen register**—a user database containing the demographic and administrative database of each citizen and the 'cornerstone' of all other modules.
- **Provider register**—a register identifying healthcare professionals and the modules which they are authorized to access.
- **Structure module**—a register identifying the physical location, functional organization, and catalogue.
- **Health record**—the 'backbone' of DIRAYA, combining and holding all the patient information associated with the NUHSA.
- **Centralised appointments**—a register of data about primary care episodes, external consultations, and diagnostic tests.
- **Electronic prescribing**—the Receta XXI module facilitates prescribing, dispensing and control of medicines. Physicians in PHC are the main users, with pharmacists able to access information about medicines prescribed and not yet dispensed.<sup>(15)</sup>

**Table 10 - Implementation of the Andalucía Electronic Health Records**

<b>Year</b>	<b>Event</b>
<b>1998/9</b>	Decision to improve PHC management by establishing DIRAYA system
<b>2000</b>	DIRAYA working groups established
<b>2001</b>	DIRAYA user database launched, generating regional identifier
<b>2002</b>	(Design) DIRAYA pilots in Seville and Cordoba. Citizens granted access to user database to update their admin info.
<b>2003</b>	DIRAYA launched, with centralised appointment booking and ePrescribing Legislation passed, guaranteeing waiting time
<b>2004</b>	Final implementation, with ePrescribing
<b>2005</b>	Appointment module for providers in primary and specialised care Legislation implemented, guaranteeing waiting time
<b>2006</b>	First EHR deployed in emergency room and specialist outpatient services
<b>2007</b>	SMS appointment module launched in primary care
<b>2008</b>	(Planning) introduction of DIRAYA to hospitals inpatient services

A patient's registered GP has automatic access to DIRAYA, as do other GPs who have consent which the patient gives using their Andalusian health system card—this is not mandatory for emergency services. Patients must give consultant specialists and pharmacists their e-card. Patients have legal right of access to their records and can choose to share confidential data only with their GP, who can also block any physician's access at the patient's request.

Using their digital certificate, patients can access the audit trail of access to their record in the Spanish national health record system. They can see who has accessed their record, including the name of the person and the organisation they worked in. In the Andalucía system it is more complicated. If a patient formally requests information about who has accessed their records, they are told the type of healthcare professional and the organisation they worked in—but not the healthcare professional's name. Privacy laws protect healthcare professionals, so the name can only be revealed if requested by a judge.

### 6.2.3 Stakeholder engagement

Patients were not consulted on the development of clinical content for, or the design of, the patient summary landing page or any content in the DIRAYA health record. Patients have the option to send feedback through the comments and complaints section within the record. Patient representative organizations are consulted in respect of policy and other developments in healthcare.

### 6.2.4 Lessons learned

The first step towards the establishment of the electronic health record system, DIRAYA, was the introduction of unique national health identifier in Spain and the regional health identifier in Andalucía. Initially, DIRAYA performance was slow, but when the technical problems were solved, many healthcare professionals appreciated it. Their suggestions for improvement also showed a 'sophisticated understanding of health informatics and ICT possibilities'.

## 6.3 Austria

A patient summary is under consideration but has not been implemented in Austria.<sup>(17)</sup> The Elektronische Gesundheitsakte (ELGA, the Austrian 'electronic health record') is a document-sharing platform that currently supports discharge summaries, laboratory results, radiology results, and electronic referrals (eReferrals).<sup>(17)</sup> A central patient register was established to support the rollout of national health card.<sup>(17)</sup> The register was 99% complete at the start of the Austrian electronic health record rollout, and provides demographic information.<sup>(17)</sup> Within the register, the central citizen identifier is hidden, and linked to the respective identifiers for specific areas, including healthcare and finance.<sup>(17)</sup>

### 6.3.1 Governance

The Austrian Ministry of Health is responsible for setting policy and for overseeing the implementation of healthcare in Austria, including implementation of the national electronic health record system, Elektronische Gesundheitsakte (Austrian electronic health record) scheme.<sup>(54)</sup> The Austrian electronic health record Act ('health telematics legislation'), the EU General Data Protection Regulation, and the Data Protection Act form part of the legislative framework for Austrian electronic health record and the proposed patient summary.<sup>(17)</sup>

Every patient is considered to have consented initially but has the right to opt out of any event being published on Austrian electronic health record.<sup>(17)</sup> They can delete or hide documents, they can totally opt out and all documents will be deleted, they can opt back in but Austrian electronic health record will not have any documents for them at the start if they do this.<sup>(17)</sup>

There is no access to Austrian electronic health record without authentication of the patient using the patient's health card—the patient must bring their health card to the consultation to allow the physician see documents.<sup>(17)</sup> Every access is monitored and stored.<sup>(17)</sup> Physicians have access to a patient's record for 28 days after authentication—unless the physician downloads the document locally.<sup>(17)</sup> Patients may limit or extend the time that the physician can access their record.<sup>(17)</sup>

### **6.3.2 Implementation**

GPs are cautious about Austrian electronic health record because a single patient could easily have many documents in Austrian electronic health record.<sup>(17)</sup> As a consequence, a GP may not find the relevant information for a patient during a consultation but would, nonetheless, be held accountable if they administer incorrect treatment.<sup>(17)</sup> Thus GPs are driving the introduction of a patient summary, to make a succinct summary of the necessary clinical information available.<sup>(17)</sup> GPs would like to create patient summaries from the structured data on Austrian electronic health record.<sup>(17)</sup> However documents in Austrian electronic health record do not always contained structured data, using free text instead.<sup>(17)</sup>

### **6.3.3 Stakeholder engagement**

Two working groups—comprised of the Austrian Physician's Chamber, hospitals, provinces, and vendors—defined the clinical content dataset for the proposed patient summary.<sup>(17)</sup> The patient summary is considered to be a clinical document, therefore a full public consultation was not considered necessary or appropriate.<sup>(17)</sup> Patient representatives sit on the user advisory group for Austrian electronic health record and patients were consulted, through patient advocacy groups, on the content and functionality of the website.<sup>(17)</sup>

### 6.3.4 Lessons learned

Programme leadership emphasised the usefulness of structured data in GP systems, and compliance with national standards, as providing a rich source of data for an automatically-generated patient summary document.

## 6.4 Denmark

A national patient summary has not yet been implemented in Denmark.<sup>(18)</sup>

The Danish standards development organization, Medcom, has investigated the possibility of generating a national electronic patient summary, to meet the requirements of the EU cross-border project, Open National Contact Point (OpenNCP).<sup>(18)</sup> Medcom has defined national standards for discharge summaries, notifications and care reporting and considers that, together, these documents would provide the information necessary to generate a Danish patient summary that complies with OpenNCP specifications.<sup>(18)</sup>

### 6.4.1 Governance

The Danish health system operates across the three political and administrative levels: national, regional and municipal.<sup>(55)</sup> The Ministry of Health has overall responsibility for coordinating and supervising health and elder care.<sup>(55)</sup> The five regions are responsible for hospitals, GPs and psychiatric care.<sup>(55)</sup> The 98 municipalities are responsible for primary care and elder care.<sup>(55)</sup> Founded in 1994, MedCom is the publicly-funded, non-profit cooperative body that develops standards and profiles for the exchange of healthcare-related data in the healthcare sector, liaising with national and international stakeholders.<sup>(56)</sup> Financed and owned by the Ministry of Health, the Danish regions and local governments, MedCom is a cooperative venture between authorities, organisations and private firms linked to the Danish healthcare sector.<sup>(57)</sup>

In Denmark, the General Data Protection Regulation is interpreted as having no concept of ownership, recognising only data processors and data controllers—that is, an organisation does not own the data, instead managing it either as a processor or controller.<sup>(18)</sup> For example, patients can control their hospital data and records, but they cannot destroy them.<sup>(18)</sup> All information governance relating to patient summaries is rooted in these GDPR concepts of data processors and data controllers.<sup>(18)</sup>



Patients can access their information through the national healthcare portal.<sup>(18)</sup> The Danish National Patient Portal, sundhed.dk, shows the national current medication record, which shows the patient's current medication based on extracts from hospital systems and other systems.<sup>(18)</sup> Patient can see who has accessed their information.<sup>(18)</sup> A general practitioner will be named, but, for technical reasons after the integration with hospital systems, hospital personnel are not named. Medcom is working to resolve this and name any hospital personnel that accessed.<sup>(18)</sup> Opting out is very unusual—for example, perhaps if a couple is getting a divorce and one party has a relative who is a doctor.<sup>(18)</sup>

#### 6.4.2 Implementation

After investigating a data model with concepts and their relationships, the Ministry for Health then focused instead on the exchange of discharge summaries, medical information and built infrastructure, to support sharing of information.<sup>(18)</sup> A new overarching architecture is now being developed.<sup>(18)</sup> While they will continue to use CDA and FHIR for document exchange, the new focus is on the direct exchange of information and sharing.<sup>(18)</sup> Currently the information is sent point to point but they may look to sharing the information to a central database, from where it can be retrieved—for example, referrals would go to a central database and a doctor could sign up for notification for referrals for that speciality.<sup>(18)</sup>

Medcom is considering each of three approaches to generating the national electronic patient summary:

- Document generated and maintained manually by the GP — this can create extra workload for GPs, even forcing them to choose from among competing systems which systems to update.<sup>(6)</sup>
- Document generated from different sources, as a persistent document — could also introduce delay—for example, a discharge summary might not be considered final, and therefore might not be sent to the patient's GP, until the final blood test results were received, several days after discharge.<sup>(13)</sup>
- Document generated from different sources, dynamically — is often based on a central national repository, the most technically complex and challenging approach of the three options.<sup>(13,18)</sup>

### 6.4.3 Stakeholder engagement

Rather than relying on regulation or legislation, Medcom develops standards based on consensus.<sup>(18)</sup> Medcom devises simple clinical use cases then builds the infrastructure to implement them, with health organisations piloting the agreed standards.<sup>(18)</sup> Medcom relies on consumer recognition of the benefits of standards and specifications—for example, by reducing the consumer’s workload—to drive market demand for compliant vendor offerings.<sup>(18)</sup>

Medcom supports the business rather than technical implementation, working with users to develop workflows for the new system.<sup>(18)</sup> Medcom does monitor the number of messages sent through the central health network, providing technical validation of messages, but does not review clinical content.<sup>(18)</sup> Medcom works closely vendors, clinicians, and healthcare organisations to develop specifications, defining the nature of the project and its purpose, as well as the information to be coded and highly structured.<sup>(18)</sup>

Establishing ownership among partners, especially doctors, was extremely important, as Medcom has found doctors to be very concerned about sharing data.<sup>(18)</sup> Therefore, Medcom has focused on supporting clinicians (such as doctors, nurses, and hospital staff) and supporting clinical decision-making as a top priority.<sup>(18)</sup> The patient portal was a spin-off.<sup>(18)</sup> When making data available to patients, they hold focus groups with patients to understand requirements then create patient-specific views.<sup>(18)</sup>

### 6.4.4 Lessons learned

The considerations for generating a patient summary were also emphasised. When the GP generates and maintains the patient summary manually, this can create extra workload for GPs.<sup>(13)</sup> Where the patient summary is generated automatically as a persistent document from different sources, lags in updates could cause delays—for example, a discharge summary might not be considered final, and therefore might not be sent to the patient’s GP, until the final blood test results were received, several days after discharge.<sup>(13)</sup>

Finally, dynamic generation of the patient summary from different sources, often based on a central national repository, is the most technically complex and challenging approach of the three options—but also the most effective.<sup>(13)</sup> Thus, the emphasis is moving away from

implementing a manually generated patient summary document to investigation of the possibility of generating documents 'on the fly' from a national central database of clinical information.<sup>(18)</sup>

## 6.5 Finland

A Patient Summary Service was scheduled to go live in Finland by early 2020. However, while the technical service is ready, some data uploaded to the national data repository must be upgraded before the service can go live. At the time of writing, the Finnish national social insurance institution, Kansaneläkelaitos (Kela), which has responsibility for the upgrade, had not provided a date for its completion.

In Finland, all healthcare providers are obliged by law to upload patient health information to the National Patient Data Repository.<sup>(19)</sup> A small subset of the data is sent to the repository as structured data, with the bulk of the data stored as free text.<sup>(19)</sup> The proposed patient summary will be based on the structured data in the national repository. Patient data is retrieved from the National Patient Data Repository using the single national identifier, the National Social Security Number, which is used for all purposes including health.

My Kanta, the Finnish National online patient portal, provides patients with a range of services including the ability to see—at organisational level—who has accessed their data in the repository. Overall, stakeholders see the value in the repository, with approximately 95% participating in the National Patient Data Repository scheme—with exemptions for small, private providers on grounds of cost.

### 6.5.1 Governance

Working within the Finnish Ministry of Social Affairs and Health, the National Institute for Health and Welfare is responsible for planning, directing and following the processing of EHRs as well as related data management and national data system services. The Data Protection Ombudsman has the competence for data protection issues. Regional State Administrative Agencies have certain controlling and supervising-related competences in their regions.

The Finnish social insurance institution, Kansaneläkelaitos (Kela) is responsible for technical implementation and maintenance of the Kanta services. Kela implements the My Kanta online patient portal services in collaboration with healthcare service providers, health record system providers and healthcare authorities. Kela is also responsible for data protection and data security of its service, taking action in case of illegal processing of health records.

Patients can view all their data in the repository using My Kanta, the online patient portal and they can see—at organisational level—who has accessed their data. They can also request more information about any access and check the organisation's legal authorisation to do so. Where an organisation supplies information, they are considered to own the data. In such cases, the patient can request that any errors be rectified but nothing more.

Governance for the patient summary project was light touch—the project was seen as largely technical in nature. The Institute project groups developed the specifications for the patient summary and its implementation. Healthcare professionals—such as doctors and nurses—were included in workgroups that reviewed the draft specifications.

### **6.5.2 Implementation**

To support GPs in meeting their legal requirement to submit data to the national repository, the Finnish Doctors' Representative Organisation provides GP system standards, a very simple and inexpensive package for creating basic, compliant GP records. Clinics and hospitals joined the National Patient Data Repository scheme, one-by-one, over a period of approximately five years, with the National Institute for Health and Welfare coordinating. The structured data in the National Patient Data Repository is limited to: diagnoses, procedures, laboratory results, dental records, images, vaccinations, medications, alerts including allergies and other risks.

The Finnish National Standard for the patient summary was published in 2014 and considered ready for national use. However, some technical problems were identified and extra content was necessary. A second version of the standard was published in 2016. At present, only some repository data is compliant with the second version of the Standard. Kela is also creating a mapping from the old format to the new.

However, a small portion of the data in the old format cannot be used. The Finnish National Standard for a patient summary has been defined, including diagnoses, allergies, procedures, laboratory results, vaccinations, alerts, and images. Originally listed as part of the national standard, medications information will now be sourced from the Finnish national prescription centre and will differ slightly from the national standard specification.

### **6.5.3 Lessons learned**

At present, the Institute is considering two approaches to the patient summary: either implementing a single document or creating a dynamic patient summary from the items in the National Patient Data Repository. While the latter gives a better result, it takes longer and is more difficult. Therefore, they suggested that, in hindsight, implementing the former—a single document—demonstrates early the potential benefits and hence ensures an early return.

## Chapter 7 Conclusion

Each country reviewed had identified the need for a succinct summary of a patient's key clinical information to be available to authorised healthcare practitioners during episodes of unscheduled care, such as treatment at an out-of-hours clinic or emergency department.

The national implementations varied considerably:

Country	Patient Summary Implemented	Description
Scotland	Implemented	Standalone patient summary system
England	Implemented	
Northern Ireland	Implemented	
Norway	Implemented	Patient summary on landing page of EHR
Andalucía, Spain	Implemented	
Finland	Scheduled	Central data repository, feeding patient summary
Estonia	Implemented	
Denmark	Under consideration	Clinical document exchange using message broker
Austria	Under consideration	Clinical document aggregation platform

Several implementations—Scotland, England and Northern Ireland—were standalone implementations that were also expected to provide learning ahead of the implementation of national shared electronic health records. These implementations provided the majority of the lessons learned. The other national implementations provided insights and best practices that are also useful.

### 7.1 Governance

As discussed earlier, the most successful implementation model is considered to be the middle-out model, where Government, industry, and clinicians collaborated to create national standards for interoperability and to encourage compliance. All the countries reviewed, except England, had used a middle-out approach. The most successful

programmes were also clinically led from the start and the emphasis was on improving clinical safety and outcomes. The implementation was seen as a partnership with stakeholders and progress made at a rate that was comfortable for stakeholders.<sup>(9)</sup>

The Scottish emergency care summary programme typified these key features.<sup>(9)</sup> In contrast with the English implementation, the programme was clinically led from the beginning.<sup>(9)</sup> The emphasis was on maximising use of existing systems, as well as simplicity, fitness for purpose, and a restrained approach.<sup>(9)</sup> The use case—emergency care only—was tightly controlled and requirements were defined with a view to ‘getting everyone on board’.<sup>(9)</sup> The programme was led by a small number of enthusiastic clinicians, and the programme engaged patients early in consultation.<sup>(9)</sup> The overall narrative was of ‘improving clinical care and assuring quality and safety’.<sup>(9)</sup>

In most countries, governance typically took the form of a national programme board, often chaired by a clinical lead and with representation from key stakeholder groups, such as professional bodies representing clinicians. Representatives from the IT sector, executive representatives from the state department and administrative health regions, and patient groups were also included on the board and in working groups. This board often reported to an eHealth function within the Department of Health. In some countries, additional boards were created to oversee day-to-day operational management and for information governance respectively.

The legislative framework varied from country to country, with existing legislation around medical and healthcare records, existing information governance legislation and the EU General Data Protection Regulation (GDPR) among other pieces of legislation forming this framework. Changes to existing legislation were generally in place ahead of programme implementation—however, in Norway, the pilot project was started before the requisite change had been made to the Norwegian Health Act because of the funding commitment in the previous year’s Budget.

## 7.2 Clinical content

Standalone patient summary implementations typically began with a clearly-defined project scope, of key clinical information to support episodes of unscheduled care in the emergency or out-of-hours situations. The availability of structured data in GP systems influenced the

clinical content of the patient summary—for example, in Scotland and Northern Ireland, the clinical dataset of medications and adverse reactions was already well-structured in GP systems. This clinical dataset had obvious clinical benefit for patients, and rapidly won public support in Scotland and Northern Ireland. It also allayed 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.

Once the patient summary was considered successful in England, Scotland, and Northern Ireland, the clinical content was extended to the chronic disease and cross healthcare setting use cases. In Scotland, the implementation for the extended dataset was phased and uptake rates were high. In England, adoption of the extended dataset was far slower than for the original implementation and stalled at 20% for a time. Therefore, the recommendation was to implement the full dataset from the outset.

As noted earlier, the medications information presented in the patient summary was typically updated automatically. One study has shown that physicians consider automatically updated information to be more reliable than manually updated information. However, such automatically updated medications list may still be incomplete—for example, not including medications that were prescribed in hospitals, drug clinics, or mental health clinics, nor any prescribed on handwritten prescriptions.<sup>(9)</sup> To address this, clinicians in England and Northern Ireland were instructed to triangulate the patient summary medications list with at least one other source—for example, the patient themselves, while the Scottish emergency care summary initially had a warning on the landing page also.

In the other implementations, the clinical content of the patient summary varied considerably and were typically far more comprehensive. Therefore, they are not considered relevant.

### **7.3 Implementation**

Experts in every country emphasised a unique national health identifier as the crucial prerequisite for any patient summary implementation—a demographics database using this health identifier was typically in place well in advance. Most of the countries reviewed used existing information sources—for example, the Scottish emergency care summary



implementation used existing infrastructure and the clinical dataset was relatively well-structured within the GP record. This often included reusing an existing national registry, based on a unique national healthcare identifier, which could be used as an automated source of identification and demographic information. An electronic prescribing service, a national patient portal, and other key eHealth systems were also usually in place, or established soon after the implementation of the patient summary.

Where the patient summary is implemented as a standalone system, interfaces should be well-integrated with current systems to avoid an adverse impact on healthcare professionals—for example, in Norway, doctors much enter their security credentials a second time in the patient summary system. When the patient summary is generated and maintained manually, this can create extra workload for GPs.<sup>(13)</sup>

The form of the patient summary document also varied. The English and Scottish implementations uploaded a PDF file, which is replaced by subsequent updates. In Norway and Andalucía, Spain, the landing page of the electronic health record system addresses the patient summary use case, being populated with the key clinical information defined in the respective national patient summary datasets. In Denmark, the national standards organisation, Medcom, has assessed and confirmed their ability to generate a patient summary from clinical documents—discharge summaries, notifications and care reporting.

In Estonian, the clinical dataset for the patient summary is held in the national central data repository and made available to authorised healthcare professionals through the Time Critical Data service. The database, which is populated by data from clinical documents, is due for upgrade or replacement. The Estonian programme is working to introduce an event-based architecture to ensure that individual data elements of all clinical documents, not just the time critical data, could be used to build a patient summary viewer—which actually addresses the Key Information summary use case for patients with chronic conditions accessing care across healthcare settings.

Where central, national data repositories have been implemented, additional options are available and possible for the generation of the patient summary—each with considerations. Where the patient summary is generated automatically as a persistent document from different sources, lags in updates could cause delays—for example, a discharge summary

might not be considered final, and therefore might not be sent to the patient's GP, until the final blood test results were received, several days after discharge.<sup>(13)</sup> Dynamic generation of the patient summary from different sources, often based on a central national repository, is the most technically complex and challenging approach of the three options—but also the most effective.<sup>(13)</sup> One expert recommended implementing a static patient summary document first, to demonstrate early the potential benefits and hence ensures an early return, as the programme to implement the more technically complex dynamically generated patient summary progressed in parallel.

Practical considerations for implementation included ensuring that a minimum number of patient summaries were available in the system – approximately 50% coverage. Otherwise, healthcare professionals encountered too many failed attempts to retrieve the record and tended to abandon use of the system. It should also be possible to retrieve and read a patient summary in 30 seconds or less, otherwise the system is not practical—for example, for the ambulance service.

## 7.4 Stakeholder engagement

In successful programmes, stakeholder engagement was considered to be a critical workstream and significant time and resources were devoted to engaging the support of all stakeholder groups. Clinical buy-in was considered critical to the overall success of the programme and the programmes were often championed by several enthusiastic clinical leaders. Success tended to be measured through clinical success stories and critical incidents, together with pragmatic audits to give an overview of key indicators.

During the early adopter phase of the English summary care record implementation, the mass media campaign (of mailshots, press coverage, and road shows) did not appear to change public attitudes to the English summary care record.<sup>(58)</sup> Instead, two credible national clinical leads were appointed and travelled across the country addressing concerns of fellow GPs' and of the public.<sup>(58)</sup> Each primary care trust also had at least one local champion—that is, a GP or senior nurse who linked the English summary care record to the improvement of care and because an expert user, educating others.<sup>(58)</sup> The study noted that a 'negative champion', challenging the project, in a strategic position could significantly impede progress.

In contrast to the English summary care record programme, the first year of the Scottish emergency care summary programme was dedicated almost entirely to establishing dialogue, negotiating with patient and clinician groups, and consulting formal organisations such as the Information Commissioners.<sup>(3)</sup> Clinical content and format were agreed in workshops and meetings with clinical groups.<sup>(9)</sup> Issues around privacy and consent were discussed at length, and patient perspectives actively solicited.<sup>(3)</sup> The resulting solutions were considered to be pragmatic and relatively light touch.<sup>(3)</sup> National and local campaigns informed both GP practices and patients about the new system, as well as the possibility of opting out.

Mechanisms for engaging stakeholder groups varied. In some countries, the patient summary was considered communication between healthcare professionals, therefore extensive patient engagement in the definition of clinical content standards was not considered necessary, though patient representative organisations were included.

For example, during the Norwegian pilot phase, reference groups—consisting of healthcare professionals, patient representative organisations, administrative personal, and healthcare professionals organisations—met every month for the first few years for the project. All groups had equal weight and had access to the same documents and information. After the pilot stage, the groups were disbanded, with group of medical experts advising on document sharing and patient organisations involved only for a specific need. This ensured engagement with all crucial stakeholders during the implementation.

In all implementations, healthcare professionals usually must have the patient's consent to access the patient summary—though there are necessary exceptions for emergency situations. Public information campaigns around consent and data sharing formed a huge part of successful implementations—such as a campaign providing a leaflet to every household in the country in Northern Ireland, reflecting that these programmes were launched before 2010. As noted earlier, the Scottish programme took a pragmatic approach to the trade-off between privacy and consent against access to data.<sup>(9)</sup>

In the standalone implementations, the recommendation was to make all clinical data available or none, rather than attempting to restrict access to part of the data, and to make the consent process as simple as possible. Where the patient summary was implemented as

the landing page in an electronic health record, the clinical dataset is more extensive and patients can restrict access to parts or all of the data. Providing patients with greater control over their data was considered to increase goodwill and engagement in the programme.

Details of all access to the patient summary are usually recorded in audit logs, though the extent of the information recorded varied from country to country—for example, in Norway, the name and workplace of every healthcare professional that has accessed the patient summary is listed but in Andalucía, the identity of the healthcare professional can only be revealed by order of a judge. Unauthorised access is typically considered a criminal offence.

## 7.5 Benefits realized

An academic study of the Norwegian summary care record programmes showed that doctors working in emergency departments found summary care records particularly beneficial for three specific groups of patients:

- unconscious patients, particularly where no information was held on file for them,
- patients using multiple pharmaceutical products, and,
- patients with a history of substance abuse.<sup>(6)</sup>

This finding was reflected in the results of a study on the Scottish emergency care summary.<sup>(6)</sup>

The Scottish emergency care summary quickly became part of 'business as usual'. By 2012, clinicians working in emergency situations in Scotland regard the Scottish emergency care summary as a key data source, being particularly useful for the medicines reconciliation process when patients are admitted to hospital.<sup>(9)</sup> In a survey of 118 clinicians (as NHS24 users), 34% said it had changed a clinical decision.<sup>(9)</sup>

## Appendix A English summary care record clinical content

The original business case for the English summary care record identified two levels of clinical content:

- **Level 1 *GP Summary***— medication, allergies and adverse reactions only, to be uploaded from the local detailed record in the GP practice. Initially uploaded as text, the summary was to be coded later and additional information included.
- **Level 2 *Additional Information***— emergency department reports, discharge summaries, outpatient letters.

Following the recommendations of the inquiries in 2010, the Dept. of Health decided to limit the scope to the minimum clinical dataset to the following: <sup>(41,42,59)</sup>

- medication
  - acute medication – prescribed in last 12 months
  - repeat medication – all from the current practice
  - discontinued repeat medication – all medications stopped in the last 6 months.
- allergies
- adverse reactions

Later, the decision was taken to evolve the product—to use different sources of data and to address the data model.<sup>(42)</sup> An Additional Information section was added, where other pertinent information can be included, with the patient's express consent.<sup>(42)</sup>

At the time of writing, the additional information includes:

- reason for medication
- significant medical history
- anticipatory care information
- communication preferences (SCCI-1605)
- end of life care information (SCCI-1580) and
- immunisations.<sup>(42)</sup>

The GP contract included extra functionality that was helpful for frail and elderly people. For example, for End of Life care has a flag, which shows the significance, and a comment

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field.<sup>(42)</sup> Ownership of medications not prescribed by primary care—that is, medications prescribed elsewhere, such as in dental practices, hospitals, or over the counter—is provided for information only in the Additional Information.<sup>(42)</sup> This information is recorded as free text, and, as such, it can be difficult to implement and to keep on top of these.<sup>(42)</sup>

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For further information please contact:

Health Information and Quality Authority

George's Court

George's Lane

Smithfield

Dublin 7

D07 E98Y

+353 (0)1 814 7400

[info@hiqa.ie](mailto:info@hiqa.ie)

[www.hiqa.ie](http://www.hiqa.ie)

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