



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

International Review of National Summary Care Records

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Safer Better Care

About the Health Information and Quality Authority

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

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

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, HIQA has statutory responsibility for:

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for health and social care services in Ireland.
- **Regulation** – Registering and inspecting designated centres.
- **Monitoring Children's Services** – Monitoring and inspecting children's social services.
- **Monitoring Healthcare Safety and Quality** – Monitoring the safety and quality of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment** – Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.
- **Health Information** – Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

Overview of Health Information function

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is therefore imperative that information is managed in the most effective way possible in order to ensure a high-quality, safe service.

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

In addition, health information has a key role to play in healthcare planning decisions – where to locate a new service, whether or not to introduce a new national screening programme, and decisions on best value for money in health and social care provision.

Under section (8)(1)(k) of the Health Act 2007, the Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care, making recommendations in relation to improving the quality, and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable

and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector, is highly fragmented with major gaps and silos of information which prevents the safe, effective, transfer of information. This results in service users being asked to provide the same information on multiple occasions. Information can be lost, documentation is poor, and there is an 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 that is 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-quality and reliable healthcare system.

HIQA is addressing these issues and working to ensure that high-quality health and social care information is available to support the delivery, planning and monitoring of services. One of the areas currently being addressed through this work programme is the investigation into summary care records. This document will examine summary care records internationally in terms of their sources of information, content and usage.

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1 Introduction

The purpose of this document is to review international evidence and best practice with regard to the development and use of summary care records. An initial desktop review of summary care records identified seven countries for in-depth examination including; England, Scotland, Northern Ireland, Wales, Australia, New Zealand and the Netherlands. All countries included in the review are strong leaders in delivering eHealth initiatives. For example, each country has achieved almost universal use of electronic health records (EHRs) among general practitioners (GPs) at above 90%.⁽¹⁾ This international review provides an overview of the current state of summary care records in other jurisdictions and provides experiences and insights of how summary care records or related initiatives (for example, shared care records or national patient summaries) have evolved in other countries.

1.1 Definition

As described by Coiera (2011), 'the summary care record extends the concept of electronic health summaries to create a continuously updated and centrally stored summary of care, extracting key data from local systems after each patient-clinician encounter'.⁽²⁾

The term 'summary care record' is used specifically in the UK to describe a summary of key medical information about a patient and uses a centralized model to store patient summaries. Elsewhere, terms such as 'patient summary' are used or a shared summary care record is used in Australia.

The definition of a summary care record that will be used for the purpose of this document is outlined below:

A summary care record is a secure structured summary of key medical information, held centrally on a national database that is accessible over a secure network from any location where a patient seeks treatment.⁽³⁾

For the context of this review, it is important to also define shared care records and clinical portals as they are closely related to the concept of summary care records.

A shared care record enables providers in primary care or hospitals to view patient records with the patient's consent, or their representative's where

appropriate. A shared care record uses existing clinical records which are accessed and stored locally. In contrast, a summary care record is not typically created by clinicians but is created 'automatically, by uploading extracts from existing records'. The summary care record is usually 'stored centrally in purpose-built systems, not locally in existing systems, and usually contains key elements such as a patient's name, address, age, allergies, current medications and diagnoses'.⁽²⁾

A clinical portal provides web access to various information technology (IT) systems to deliver patient summaries. Clinical portals can range from being simplistic, providing the user with access to information, through to being highly interactive, supporting functions such as booking appointments or adding clinical information to an electronic health record. Clinical portals are also more likely to be mobile enabled given consumer demand for such devices.⁽⁴⁾

1.2 Project background

Under the Health Act 2007⁽⁵⁾, the Health Information and Quality Authority (HIQA) has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies on health information, as follows:

- Section 8(1) (i) to evaluate available information respecting the services and the health and welfare of the population. Section 8(1)(j) to provide advice and make recommendations to the Minister for Health and Children and the Health Service Executive (HSE) about deficiencies identified by the Authority in respect of the information referred to in paragraph (i).
- Section 8(1)(k) to set standards as the Authority 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.

HIQA is fulfilling this remit by undertaking this international review of summary care records. This review provides information on the development of summary care records for England, Scotland, Northern Ireland, Wales, Australia, New Zealand and The Netherlands. Each of these countries are at different stages in their development of summary care records.

1.3 Overview of summary care records

Healthcare is under increasing pressure to harness the benefits of information. Patients expect their health information to be recorded, processed and used appropriately for their benefit. Healthcare professionals require access to complete, valid and up-to-date health information in order to make informed choices and decisions, for example, deciding on a treatment or care programme. In order to meet these demands a number of countries have focused on the development of summary care records.

1.3.1 Benefits of summary care records

Healthcare providers and patients can benefit from the introduction of summary care records. Professor Iain Carpenter from the Royal College of Surgeons in England argues that 'the summary care record represents a major resource for improving patient safety. There is no doubt that physicians should use it when needed'.⁽⁶⁾ The UK Health and Social Care Information Centre summarise the main benefits of summary care records for patients and providers which are outlined below.⁽⁷⁾

The main benefits of summary care records experienced by patients include:

- improving patient experience – for example, a patient does not need to organize or remember a list of their medications and it reduces the number of times a patient has to repeat their clinical information to healthcare staff
- improving patient safety - for example, making sure a new drug does not affect how another drug works
- improving the effectiveness of patient care – by giving healthcare staff relevant information to make appropriate decisions about patient care
- improving the efficiency of patient care - reducing the time, effort and resources required to obtain key information from a GP.

The main benefits of summary care records experienced by healthcare providers include:

- empowering health professionals by providing consistent, accurate, accessible information
- improving patient safety by providing timely access to accurate information which supports safer and more informed prescribing
- improving the efficiency of patient care by reducing the time, effort and resources required to obtain key information from the patient's GP
- improving the effectiveness of patient care by supporting the delivery of appropriate care to patients
- improving patient experience by reducing the requirement on the patient to repeat their medication information and supporting people with difficulty communicating.⁽⁷⁾

1.4 International review

The countries that are reviewed in detail in this report are England, Scotland, Wales and Northern Ireland, Australia, New Zealand and the Netherlands. The countries were chosen as a result of a desktop review that identified their commitment to eHealth initiatives such as summary care records or similar electronic health summary initiatives. An additional factor contributing to the selection of these countries for review is the availability of information in the English language. For the countries examined, a number of factors were considered such as, the structure of the healthcare system and the source, content and usage of a summary care record. The following sections will outline the summary care record initiatives that have taken place in England, Scotland, Northern Ireland and Wales and also provide a summary of the projects developed in Australia, New Zealand and the Netherlands.

2 England

2.1 Introduction

The population of England is 54.3 million.⁽⁸⁾ The NHS and 211 Clinical Commissioning Groups are responsible for running the majority of NHS services in the country. The NHS is also divided into a number of trusts which have responsibility for providing care across different health services such as acute hospital services and ambulance services.

2.2 eHealth in England

Health information has received much attention in the last few decades in England and has been covered in a number of publications, including 'Information for Health and Information Strategy for the Modern NHS from 1998 – 2005'. This strategy set out 'a radical programme to provide NHS staff with the most modern tools to improve the treatment and care of patients and to be able to narrow inequalities in health by identifying individuals, groups and neighbourhoods whose healthcare needs particular attention'.⁽⁹⁾

A National Programme for Information Technology was initiated in 2005 and led by the NHS Connecting for Health for the delivery of a shared, centralized electronic health record.⁽¹⁰⁾ The size and complexity of the programme was vast, with an original forecast of £12.7 billion to fund the 10-year initiative making it the largest civil, non-military information technology project ever undertaken.⁽¹¹⁾ It was termed the 'world's biggest civil information technology programme' and described by critics as ambitious and inherently risky.⁽¹²⁾

There was a change of government in the UK in 2010 and the NHS came under review which significantly impacted their eHealth policy.⁽¹³⁾ The National Programme for Information Technology was formally discarded in late 2011 in favour of locally-developed electronic record systems. However, some notable progress continued to be made in relation to national projects such as, a secure national network infrastructure called the 'N3', a picture archive and communications system, an electronic booking service called 'Choose and Book', the NHS Electronic Prescription Service and the summary care record. A previously linked programme to create a patient portal called HealthSpace for the summary care record was abandoned in 2012 because of very low uptake.⁽³⁾

In 2013, the NHS took on full statutory responsibilities for the planning and delivery of healthcare across England. Prior to this, it was the responsibility of the Department of Health, strategic health authorities and primary care trusts. The NHS published a 'Five Year Forward View' in 2014 which set out a vision for the future of the NHS based around new models of care.⁽¹⁴⁾ The ability to

'exploit the information revolution' formed an integral part of the report. The National Information Board, a body that provides informatics services for health and social care in England, developed a roadmap with key elements that include: comprehensive transparency of performance data, NHS accredited health apps for patients, fully interoperable electronic health records and family doctor appointments, and electronic and repeat prescribing.

The government's target is to introduce a comprehensive system of electronic health records in England by 2020. It is intended that each patient's electronic health record will include information about their medical history, care preferences and lifestyle, such as diet and exercise. Some of the features should include enabling a patient to view and make notes and comments to a version of their health record online. The records should be accessible to all health and social care providers and updated in real-time. In addition, patients should also be able to book appointments and order repeat prescriptions online. In England, electronic health record planning is managed by the NHS England, the National Information Board and the Health and Social Care Information Centre. The information centre is developing national standards for electronic health records, but local areas can choose their own systems.⁽¹⁵⁾

2.3 Health and Social Care Information Centre

The Health and Social Care Information Centre in England is the national provider of information, data and information technology systems for health and social care and has been operational since 2013. In July 2016, the information centre changed its name to NHS Digital. The information centre is an executive non-departmental public body, sponsored by the Department of Health and working closely with national organizations such as the NHS, the Department of Health and the bodies that commission its services. The information centre works under the National Information Board. Their work includes 'publishing more than 260 statistical publications per year, providing a range of specialist data services and managing informatics projects and programmes, and developing and assuring national systems against appropriate contractual, clinical safety and information standards'.⁽¹⁶⁾ The information centre is responsible for England's summary care record.

2.4 England's summary care record

England's summary care record was introduced as part of the National Programme for Information Technology via a programme board within

Connecting for Health. The summary care record had a high-rate of uptake and has been implemented nationally in England since 2008. It is intended that every patient in England will have a summary care record unless they choose to 'opt-out' of the programme and not have one.

The NHS England currently holds patient information both in paper form and electronically. Electronic records are stored in various settings such as GP practices, hospitals (notably in radiology and pathology), mental health providers and in some community care settings. However, there is great variety in the type and uses of electronic record systems between different settings.⁽¹⁵⁾ To help improve the sharing of important information about patients, the NHS in England is using an electronic record called the summary care record.

Source

A summary care record is a summary of the NHS patient data held on a central database and used to support patient care. The summary care record is stored on a centralized system called the NHS Spine which is a collection of national applications, systems and directories that facilitate the exchange of information across national and local information technology systems.⁽¹⁶⁾ An individual's summary care record is accessed nationally by authorized healthcare staff, based on strict access control measures. The summary care record is created by extracting a subset of information or summary of medical information from the detailed medical record held by a GP.⁽¹⁷⁾

Content

The purpose of the summary care record in England is to make patient data readily available anywhere that the patient seeks treatment. The summary care record contains only essential or the minimum core information about a patient that is needed in an emergency or an out-of-hours care setting. At a minimum, healthcare professionals have access to the core content of the summary care record that includes:

- prescribed drugs
- known adverse reactions to drugs
- known allergies.

In addition to the core content, there is detailed personal health-identifying information that is contained within the summary care record including:

- name
- address
- date of birth

- unique NHS number.

An authorized healthcare professional can also add additional information to the summary care record given that the patient, or their representative where appropriate, requests and consents to it. This can be of particular benefit to patients with detailed and complex health problems. The Health and Social Care Information Centre outline additional information for inclusion in the summary care record including:

- long-term or chronic health conditions such as asthma, diabetes, heart problems or rare medical conditions.
- relevant medical history including clinical procedures, why the patient is on a particular medicine, the care the patient is currently receiving and clinical advice to support the future care of the patient.
- healthcare needs and personal preferences – communication needs, a long-term condition that needs to be managed in a particular way, legal decisions or preferences about care.
- immunisations – details of previous vaccinations, such as tetanus and routine childhood jabs.

Specific sensitive information such as any fertility treatments, sexually transmitted infections, pregnancy terminations or gender reassignment is not included, unless it specifically requested otherwise by a patient.⁽¹⁸⁾

Usage

The summary care record provides authorized healthcare staff with faster, more secure access to essential patient information. The summary care record is currently used in emergency and unscheduled care and community pharmacy settings.⁽¹⁹⁾ As of August 2015, the statistics from Health and Social Care Information Centre in England in relation to summary care records were that nearly “55 million people in England (96% of the population) have a summary care record created from over 7,500 GP practices”.⁽⁷⁾ The information centre also maintain that “29 minutes is the amount of time that a hospital clinician can save by looking at a patient’s summary care record and up to £7 million is realised through the summary care record use every month in hospital pharmacies and GP out of hour services”.⁽⁷⁾

In June 2015 the information centre was commissioned by the NHS to lead on the introduction of summary care records in community pharmacies. By May 2016 1,000 community pharmacies went live with the summary care record. Pharmacists have access to a patient's key clinical information from their GP record including, medicines, allergies and adverse reactions. This saves time and reduces the need for a pharmacist to verify medication details with a GP.

3 Scotland

3.1 Introduction

Scotland has a population of 5.3 million.⁽⁸⁾ It is a constitutional monarchy and has its own parliament. NHS Scotland provides free healthcare to all Scottish citizens or UK permanent residents. Additionally, private healthcare is available to anyone who is willing to pay for it directly themselves. Responsibility for health and for health services rests with the Scottish Cabinet Secretary for Health and Sport who is accountable to the Scottish parliament. Supported by officials in the Scottish government's health and social care directorates, ministers set policies and oversee the delivery of NHS Scotland services. Many of the ministers functions are delegated to 14 NHS Scotland boards who are responsible for the planning and delivering of all health services including acute, primary and community services in their areas.⁽²⁰⁾

A variety of services are provided across several care settings including general medical services providing primary and out-of-hours care. Other services include general hospitals for emergency and elective services, and tertiary or specialist hospital services. It also extends to community, pharmacy, ambulance and dental services. The health boards govern the performance of these individual health services and how they communicate with each other.⁽²¹⁾

3.2 eHealth in Scotland

The most recent eHealth strategy (2011–2017) for Scotland places the citizen at the centre and seeks to build on the progress of earlier eHealth projects in Scotland over the last decade. Five strategic aims were identified in the current eHealth strategy including 'supporting people to communicate with NHS Scotland, contributing to care integration, improving medicines safety, enhancing the availability of information for staff and maximising efficient working practices'.⁽²²⁾ Various key national eHealth programmes and projects have been delivered by the Scottish government's eHealth directorate in partnership with NHS Scotland boards. They include initiatives such as, a chemotherapy electronic prescribing and administration system, national community health index programme (the NHS Scotland's unique patient identifier), a national eReferral programme, picture archiving and communications programme, ePharmacy programme and a national emergency care summary. The 'building blocks' of a national technical

architecture have also been established including standards, principles and access to enabling technologies.⁽²²⁾

3.3 Emergency care summary (Scotland)

Scotland has a summary care record called the emergency care summary. The emergency care summary is a summary of an individual's health information that can be accessed by authorized healthcare professionals if urgent medical care is required. Patients have the right to 'opt-out' of the emergency care summary project. The project was clinically led from the beginning and involved meetings and workshops within clinical groups to gain consensus about the format and content required for the emergency care summary. The emergency care summary project had strong backing from the Scottish GPs' committee of the British Medical Association.⁽²³⁾

Source

Scottish primary care has an excellent uptake of technology with more than 90% of GP practices being paperless.⁽²⁴⁾ The emergency care summary facilitates authorized providers to view the most up-to-date patient information regarding medications (which are GP prescribed) and allergies. This information is sourced from GP practice management systems and facilitates healthcare professionals working in out-of-hours or in secondary care services, such as hospitals.

Content

The core minimum content contained in Scotland's emergency care summary incorporates current and discontinued medication, adverse reactions and demographic details. The type of information uploaded from GP records includes:

- prescribed medication
- drug reactions
- allergies.

In addition to the core content, detailed personal health-identifying information that is contained within the emergency care record includes:

- patient's name
- address
- date of birth
- name of GP surgery or office
- contact information

- community health index number (Scotland's unique patient identifier).

Usage

The emergency care summary is widely used and holds key clinical information for over 5.1 million patients. Approximately 2,000 people chose to 'opt-out' in the early stages of the programme and this proportion has not changed subsequently.⁽²³⁾

Various healthcare professionals in Scotland have access to the emergency care summary including clinicians, administrative staff and healthcare professionals in emergency care situations, out-of-hour's care, the NHS24 (which is Scotland's national telephone triage system), paramedics in the Scottish ambulance service, staff in hospitals and hospices.⁽²⁵⁾

Hospital based pharmacists are also able to review and update lists of medications and plans. In 2015, dentists in Scotland were granted access to the emergency care summary. This included both dentists who work in out-of-hours services and the public dental services.

3.4 Key information summary

In 2013 the key information summary was launched to build on the progress already made with the emergency care summary, including reusing infrastructure and processes. The key information summary is an extension of the emergency care summary and so in addition to the information available on emergency care records (that is to say, patient demographics, medications and allergies) the following information may also be included:

- past medical history
- baseline functional and clinical status, including the patient's capacity
- triggers for deterioration
- current care needs and arrangements
- emergency contacts and next of kin details
- how far to escalate care
- preferred place of care, and final care plans including other specific patient or carer wishes
- palliative care information

- legal issues such as power of attorney
- resuscitation decisions
- special alerts, for example around staff safety
- free text section of the key information summary designed to provide a summary of the most relevant clinical and social information for a particular patient.⁽²⁶⁾

The key information summary was made available to all GP practices in Scotland. The key information summary aimed to facilitate more detailed sharing of information between GP systems and other systems such as the NHS24, out-of-hours GPs, secondary care and hospices. In 2015 approximately 2% of people had a key information summary and were selected by their GPs based on their complex health and social care needs.

4 Northern Ireland

4.1 Introduction

Northern Ireland has a highly integrated health and social care system serving a population of 1.8 million.⁽²⁷⁾ Healthcare is free at the point of delivery, similar to the NHS in England. However, unlike the NHS, health and personal social services are integrated in Northern Ireland to include social care services such as home care services, family and children's services, day care services and social work services. The Department of Health has overall responsibility for health and social care in Northern Ireland. Operational responsibility for health and social care is delivered through a number of bodies including the Health and Social Care Board, the Patient and Client Council, the Public Health Agency, and the Business Services Organisation. These bodies are regulated by the Regulation and Quality Improvement Authority. The NHS in Northern Ireland is referred to as Health and Social Care Northern Ireland. The health and social care services are directly provided through five regional Health and Social Care trusts. The trusts became operational in 2007 and were created from a merger of 19 former trusts. They manage and administer hospitals, health centres, residential homes, day centres and other health and social care facilities as well as providing a wide range of health and social care services to the community.

4.2 eHealth in Northern Ireland

There has been a wide commitment to eHealth in Northern Ireland over the past decade. The development of a 'Connected Health' agenda has been a ministerial priority in Northern Ireland and was outlined in the review of Northern Ireland's provision of health and social care entitled 'Transforming Your Care' published in December 2011.⁽²⁷⁾

Northern Ireland's eHealth strategy, "eHealth and care strategy for Northern Ireland", was launched in 2016 outlining the main focus of eHealth activity until 2020. As well as helping the public to use online services, such as booking GP appointments and ordering repeat prescriptions, the strategy sets out a long-term vision of implementing a fully integrated electronic health record known as the Northern Ireland electronic care record.⁽²⁸⁾

The eHealth and social care programme within the Health and Social Care oversees a number of regional projects being delivered by the Business Services Organisation information technology services. The eHealth and social care programme is working towards three strategic goals:

- 'Electronic care records containing the information and images generated from patient contacts
- Electronic care communications enabling fast, secure exchange of information between care professionals within and between the various HSC organisations
- Electronic information providing patients, service users and care professionals with details of best practice and up-to-date information for making decisions about diagnosis, treatment and the services available'.⁽²⁹⁾

4.3 Northern Ireland's emergency care summary record

In 2010 Northern Ireland introduced an emergency care summary record. The emergency care summary record mirrored the Scottish emergency care summary model in terms of the technology, information sources used and the fact that it was clinician led. Much of the success of the programme has been attributed to it already having been implemented nationally in Scotland with the support of clinicians. The emergency care summary record is a summary care record that draws key clinical information from a range of existing hospitals, GPs and community-care information systems.⁽²⁹⁾

Source

Data is extracted daily from all GP practices and is available for access by authorized staff. This includes all five Northern Ireland out-of-hours centres, all 10 accident and emergency departments and hospital pharmacy departments.⁽²³⁾

Content

The emergency care summary record was originally introduced to GP out-of-hour services, emergency departments and hospital pharmacies across Northern Ireland. The emergency care summary record includes the patient's:

- current medication
- known allergies.

In addition to the core content, detailed personal health identifying information that is contained within the emergency care summary record includes:

- patient's name,
- date of birth
- gender

- address
- telephone number.⁽²⁸⁾

However, detailed medical notes are not included in this record.

Usage

The emergency care summary record shares details of medications and allergies held on GP practice computer systems with the Northern Ireland electronic care record.

4.4 The Northern Ireland electronic care record

The Northern Ireland electronic care record is a region-wide record. The electronic care record links core information systems from hospitals and clinics throughout Northern Ireland and includes lab tests, x-rays, appointments, discharge and clinic letters, and details of any drugs prescribed and allergies recorded from GP systems. The electronic care record can only be accessed over the Health and Social Care secure network and patient data can be accessed only by Health and Social Care staff. The electronic care record was implemented in 2013 and was successfully adopted across the Health and Social Care connecting acute and community hospitals, as well as all GP practices and community and mental health units. Authorized healthcare professionals have access to patient data extracted from local information systems and the emergency care summary record.

As outlined in the Northern Ireland eHealth strategy (2016), the aim is to develop a fully integrated electronic healthcare record using the current technology in the Northern Ireland electronic care record to connect specialist systems. We will ensure that community pharmacists, dentists, opticians, and independent health and social care providers (such as nursing homes) have secure and appropriate access to Northern Ireland electronic care record/emergency care summary record information. We will develop this to allow them to contribute directly to a person's health and care record'.⁽²⁹⁾

5 Wales

5.1 Introduction

NHS Wales is the publically funded National Health Service of Wales providing healthcare to a population of 3 million. NHS Wales delivers services through seven health boards and three NHS trusts in Wales. The seven local health boards plan, secure and deliver healthcare services in their areas. Additionally, the three NHS trusts cover all of Wales and include the Welsh Ambulance Services Trust for emergency services, Velindre NHS Trust offering specialist services in cancer care and a range of national support services, and the new Public Health Wales.⁽³⁰⁾

5.2 eHealth in Wales

A national organization, the NHS Wales Informatics Service, was established in 2010 with responsibility for the development and support of the health and social care technology used throughout Wales.⁽³¹⁾ Some of the key informatics projects in Wales include the GP record (individual health record), demographic services, clinical portal and 'My Health Online' (a service that gives the patient the option to book an appointment online to visit a GP or order a repeat prescription).

5.3 Welsh individual health record

In 2005 NHS Wales collaborated with patient groups, local GPs and several medical organizations to agree on the development of an emergency care individual health record for Wales. The individual health record is a summary of the patient's GP record, which is made available to clinicians working in unscheduled care settings. It holds information about the patient's medical history, such as medication, allergies and recent care. The aim of the individual health record is to provide better information for medical staff providing out-of-hours and emergency care in order to help improve the quality and safety of patient care. A health professional must have the patient's consent before accessing the Welsh GP record, unless the patient is unable to do so.

Source

The individual health record is a copy of relevant information from GP records which allows medical staff (GPs and nurses) in local out-of-hours services to view basic information about a patient's medical history.

Content

The content of the individual health record includes the following key data:

- medication (current and past)
- medical problems
- recorded allergies
- test results.

The last two years of medication history are displayed and one year of the test results are displayed. Patient and GP details are also included and consist of:

- patient name, address and contact details
- details of current GP practice.

The individual health record does not include details on:

- sexually transmitted diseases
- HIV or AIDS
- human fertility and embryology
- terminations
- gender reassignment
- private discussions between a patient and a GP.⁽³²⁾

Usage

By mid-2012 nearly 65% of GP practices had gone live with the individual health record for more than 2 million patients. The individual health record was also piloted on six wards for unscheduled admissions in Cardiff's University Hospital, Wales. There was a positive reaction to the three month pilot with clinicians saying it 'saves time, not just for themselves, but for the GPs they would normally have to contact'.⁽³²⁾ Eventually, it is envisaged that the individual health record will be available to medical staff in other emergency and urgent health care settings.

6 Summary of findings from England, Scotland, Northern Ireland and Wales

England, Scotland, Northern Ireland and Wales each began a programme to introduce a summary care record between 2004 and 2008.⁽²³⁾ Greenhalgh et al (2013) conducted an evaluation study on the summary care record in the UK inclusive of England, Scotland, Northern Ireland and Wales.⁽²³⁾ The study concluded that despite the benefits that can be derived from the use of summary care records, implementation of a nationally shared electronic summary record is highly challenging which requires multiple overlapping tasks.

Table 1 outlines some of the key characteristics that were identified in relation to the demographics and structure of each healthcare system alongside the source, content and usage of the summary care record. There was much in common between these four programmes of work. For example, all summary care records source extracts of information from the record held by the patient's NHS GP which were accessible by authorized staff via a secure connection. England, Scotland and Northern Ireland have the same core minimum summary of information that includes; medications, adverse reactions and or allergies and health identifying information. Wales also has the same minimum dataset as the other three countries but also includes medical problems and test results. England, Scotland, Northern Ireland and Wales all have widespread use of summary care records in their jurisdiction.

Table 1. - Summary of the UK summary care record

Criteria	England's Summary Care Record	Scotland's Emergency Care Summary	Northern Ireland's Emergency Care Record	Wales' Individual Health Record
Population	54.3 million	5.3 million	1.8 million	3 million
Scope and purpose of summary care record	Emergency and unscheduled care community services and end-of-life care.	Emergency care.	Emergency care.	Emergency and out-of-hours care.
Source	A summary of medical information is extracted from a detailed medical record held by a GP.	This information is sourced from GP practice management system in GP practices.	Data is extracted daily from all GP practices and accessed by authorized staff.	This information is a copy of relevant information from GP records.
Core Content	Patient's medications, adverse reactions, allergies, and health identifying information.	Patient's name, address, date of birth, name of GP surgery contact, community health index number, medication and drug reactions and allergies.	Patient's name, date of birth, gender, address, telephone number, current medication and any known allergies.	Patient's name, address, contact details, current GP practice, medication history, medical problems, recorded allergies and test results
Usage	55 million people in England (96% of the population) have a summary care record created from over 7,500 GP practices.	Key clinical information for over 5.1 million patients.	An emergency care summary record is available via the electronic care record and is adopted across acute and community hospitals, GP practices and community and mental health units.	There is an individual health record for more than 2 million patients.

7 Australia

7.1 Introduction

Australia has a population of 23.5 million⁽³³⁾ and citizens have access to a high standard of healthcare funded mainly through public taxation.⁽³⁴⁾ The Commonwealth of Australia is comprised of six states and 10 territories. A federal system of government is in place with power shared between the Commonwealth government and the six state governments. Two internal territories and one island territory hold a limited right to self-govern.⁽³⁵⁾

The healthcare system consists of both public and private providers. The Australian Government funds rather than provides health services. There is a large private health sector.⁽³⁴⁾ However, private health insurance is not compulsory.⁽³⁶⁾ Healthcare providers deliver multiple services from public health and preventative services in the community, to primary healthcare, emergency health services, hospital-based treatment, and rehabilitation and palliative care. Private sector health service providers include private hospitals, medical practices and pharmacies.

7.2 eHealth in Australia

There are a number of councils, organizations and committees involved in health information in Australia. This includes the Australian government, the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, the Department of Health, the Department of Human Services and the National eHealth Transition Authority.

The National eHealth Transition Authority is a not-for-profit agency established by the Australian government in 2005. It is a private company that leads a national approach to eHealth to support private, national, state and territory reforms, by developing a national eHealth infrastructure and is funded by the Commonwealth and state and territory governments. The National eHealth Transition Authority was responsible for delivering the national eHealth strategy. This includes outlining a national infrastructure for delivery of a future individual electronic health record. The National eHealth Transition Authority's principal aim is to provide national infrastructure, accelerate adoption of the strategy and build towards a future individual electronic health record service. The new Australian Commission for eHealth will begin to take on e-health roles of the Department of Health and the National eHealth Transition Authority in July 2016.⁽³⁷⁾

7.3 Australian 'My Health Record'

There has been substantial progress regarding eHealth activities at a national level in Australia. The Commonwealth government approved the development of the Personally Controlled Electronic Health Record system in 2010 and allocated funding to deliver this by July 2012.⁽³⁸⁾ It is now known as the 'My Health Record' system. The My Health Record is an electronic summary of a person's health information. The My Health Record contains online summaries of an individual's health information, such as medicines, allergies and any treatments a patient has received.

The My Health Record is a secure online summary of an individual's health information. Healthcare providers can view an individual's health information and are also able to add and upload information about a patient's health to the record. Patients can control their own My Health Record by choosing what healthcare provider organizations can access their record and what information should be included. Individuals can register for a record and can then access their own record online. There are over 2.7 million people registered for a record. There is also more than 8,500 healthcare providers connected and approximately 570,000 clinical documents have been uploaded.⁽³⁸⁾

7.4 Australian shared health summary

The information stored on My Health Record can include clinical documents about a patient's health including their shared health summary. The shared health summary is one of the information sources for the My Health Record.

The most recently uploaded shared health summary in an individual's My Health Record will typically be the first document that is accessed by any other healthcare professional viewing a patient's My Health Record. The shared health summary is usually created by the patient's GP but can also be created by the patient's regular medical practitioner, a registered nurse or an aboriginal health worker.⁽³⁹⁾

The shared health summary signifies the patient's status at a point in time. The structure of the shared health summary is underpinned by the Royal Australian College of General Practitioners template for a GP health summary. The shared health summary can be created or updated at any consultation. The content may include information about a patient's:

- current medical condition
- medicines
- allergies

- adverse reactions
- immunisations
- demographics and health identifying information.

The healthcare provider automatically becomes the patient's 'nominated healthcare provider' by uploading the shared health summary. A patient can have only one nominated healthcare provider at a time. It is acknowledged that the shared health summary is particularly beneficial for patients with chronic conditions and co-morbidities.⁽³⁸⁾

8 New Zealand

8.1 Introduction

New Zealand has a population of 4.68 million.⁽⁴⁰⁾ It is a parliamentary democracy, an independent country and a constitutional monarchy. The Minister of Health, with the cabinet and government, develops policies and provides leadership for the health and disability sector.⁽⁴¹⁾ The National Health Board, holds responsibility for the funding, monitoring and planning of district health boards and designated national services, and for national, regional and local integration.⁽⁴²⁾

The structure and funding of public health and disability services are set out in the New Zealand Public Health and Disability Act 2000. Twenty district health boards are responsible for providing or funding the provision of health services in their district. The government's eHealth goal is universal electronic access to a core set of patients' personal health information. Given that the district health boards are autonomous, there is a strong tendency for local services to take precedence over national projects.⁽⁴³⁾

8.2 National Health Information Technology Board

The National Health Information Technology Board is a sub-committee of the National Health Board. The role of the board is to provide strategic leadership on health information systems. The board promotes national systems to support key clinical specialities including maternity, older persons, cardiac health and cancer. National systems can improve equity of access and consistency of care by reporting on quality initiatives and long-term trends. Some examples of work delivered during 2015 include:

- enabling information to be shared across disciplines for the delivery of maternity and neonatal services at the frontline through the national maternity clinical information system,
- providing a comprehensive view of the patient's secondary healthcare referral pathway to measure access to elective and cancer services through the National Patient Flow collection,
- introducing electronic systems into hospitals and the community to ensure accurate, up-to-date information about people's medications is accessible to support safe, effective and appropriate use of medicines through the eMedicines programme,
- rolling out community prescribing, which has been completed by almost all community pharmacies and has been installed in 36 general practices through the New Zealand Electronic Prescription Service.⁽⁴⁴⁾

A new 'IT update for 2015 to 2020' was announced in 2015 and is currently in the design phase. Six components have been set up to enable this:⁽⁴⁵⁾

- informatics professionals
- health professionals
- digital hospital
- vendors and integration
- consumers
- architecture and standards.

The national health IT plan identified four priorities for investment in information technology from 2014 and beyond including; electronic medication management, national clinical solutions, regional information platforms, and community-based integrated care initiatives.⁽⁴⁴⁾

8.3 eHealth in New Zealand

New Zealand has invested significant effort in the area of eHealth. New Zealand's progress on interoperability is well noted, with standard messaging allowing different care providers to communicate with each other. Since 2010, the National Health Information Technology Board has led the development of New Zealand's current electronic health record policy. Patient and provider portals can be made available to health care professionals to allow information to be captured at the point of care. This is possible by implementing a range of electronic messages such as referral and discharge summaries which covers the exchange of health records from GP to GP.⁽⁴³⁾

8.4 Shared Care Record (New Zealand)

The shared care record is a provider portal that enables health providers to safely and easily access a summary record of patient information through a secure connection. The National Health Information Technology Board, the Primary Health Organizations and GPs are working together to give patients access to their health information through a patient portal. The provider portal forms the foundation for the patient portal. In April 2015, the Health Minister launched a campaign to raise awareness of the benefits of patient portals. The board outlined the benefits of a provider portal to include 'saving time, money and reducing waiting times. Patients do not have to repeat information as often and duplicate tests such as x-rays and laboratory requests can be avoided'.⁽⁴⁶⁾ This greatly increases patient safety and can reduce admissions.

Patients are given the option to 'opt-out' of the shared care record or they can choose to withhold some information. Clinicians must seek a patient's permission before they access the shared care record. It is the responsibility of the patient's GP to inform their patients about the shared care record and to ensure patients are aware that their health information will be available to other clinicians who are authorized to use the shared care record.⁽⁴⁷⁾

Source

A provider portal can receive information from a GP system and allow access to personal health information. For example, when patients attend an emergency department or an out-of-hour service, clinicians can view the patient's primary care information through a link to GP records.⁽⁴⁷⁾

Content

Information in the provider portal includes:

- demographics
- summary of recent and long-term conditions
- hospital visits
- lab and x-ray results
- medications and allergies
- community care
- e-referrals and discharge summaries

Usage

The shared care record is wide-reaching and can be accessed by a variety of services including, hospital emergency departments, hospital in- and out-patient departments, after-hours medical centres, paramedic and ambulance services, general practice, elderly care facilities and community pharmacies.⁽²⁾

The provider portal was launched in 2014 and has been implemented at the MidCentral district health board and has been live at Wairarapa district health board since 2011. GPs are also able to view the shared care record on an as-needed basis. The introduction of the shared care record was a significant project which involved GPs installing an application called ManageMyHealth on their practice management systems. It then involved uploading patient data into the shared care record portal.⁽⁴⁷⁾

There is an upward trend of patient portal uptake continuing for both GPs and individuals. As outlined by the National Health Information Technology Board

'between June and September 2015, there was a 50% increase in the number of practices implementing the service, with over 270 practices offering patient portals. Similarly, there was a 24% increase in the number of individuals registered for portal access during the same period'. It is estimated that there would be approximately 100,000 registered portal users by the end of 2015. An awareness campaign is ongoing until mid-2016 to encourage more GPs and individuals to start using portals.⁽⁴⁸⁾

8.5 Case study: the Compass summary care record

The Compass summary care record operates throughout central New Zealand and the project covers approximately 10% of New Zealand's population. The Compass summary care record consists of a specific set of summary information that is sourced from the GP's practice management system and stored in a local cloud facility. The summary information is available in a read-only format to local authorized healthcare providers.

Forty-five practices supplied information to the Compass summary care record in the Wararapaand Capital and Coast district health board areas.

Approximately 80% of patients in those regions have a summary record in the Compass summary card record. The data supplied to the online record consists of:

- prescribed medicines
- problem list of diagnoses and conditions
- allergies
- immunisations
- recall
- laboratory results.

There is potential to add more information such as patient notes. The Compass summary care record was populated based on the assumption that all patients on the Primary Health Organizations population register would have their information transferred unless they opted out or their GP opted out for them. However, once an initial transfer takes place, further transfers would be on an 'opt-in' basis.⁽⁴⁹⁾

9 The Netherlands

9.1 Introduction

The Netherlands has a population of approximately 17 million people.⁽⁵⁰⁾ The Dutch political system is made up of a parliament which includes a senate and a house of representatives and it is considered a parliamentary democracy. Its health and social care system is based on mandatory health insurance.⁽⁵¹⁾ The main organizations responsible for the healthcare system include the Ministry of Health, Welfare and Sport, municipal health services (or local authorities) and private healthcare suppliers. These organizations cooperate together to deliver health services. The Ministry governs and implements health policy covering national, regional (made up of 12 provinces) and local (approximately 500 municipalities) level.⁽²⁷⁾ However, the role of the Ministry in delivering health services is limited as various private healthcare suppliers, including individual practitioners as well as care institutions, provide the actual healthcare services. In 2006 there was a major reform in the Dutch healthcare system and health insurance became mandatory for all citizens with the introduction of a single compulsory insurance scheme.⁽⁵¹⁾

9.2 eHealth in the Netherlands

The Netherlands are one of the EU's leaders in relation to eHealth, scoring above average utilization rates in almost every aspect of eHealth.⁽⁵²⁾ Most medical records are updated electronically and are no longer available in paper format. A 2015 survey from the National IT Institute for Healthcare and the Netherlands' Institute for Health Services Research demonstrates that 98% of GP practices are computerized and 75% of medical specialists update their records primarily or exclusively electronically. It is also reported that around 71% of GP practices use ePrescribing systems as standard.⁽⁵²⁾

The Dutch government recently published a policy paper stating its targets for eHealth deployment in the coming years. This paper defines three concrete targets to be achieved within the next five years:

- '80% of the people with a chronic disease will have online access to his/her medical data;
- 75% of the people with a chronic disease and vulnerable elderly can monitor their health status at home;
- Everyone receiving care and support at home, will have the possibility to receive 24/7 video consultation'.⁽⁵³⁾

However, in the past many eHealth systems were developed separately in various silos. This prompted the establishment of the National IT Institute for Healthcare in 2002 to facilitate the exchange of data between healthcare providers. The institute is an independent agency whose main function is to develop health information standards.⁽⁵⁴⁾ One of the main assets of the Dutch healthcare system is the AORTA which is the national, standardized infrastructure for exchanging medical records and was the underlying national infrastructure for a national electronic healthcare record¹. Instead of deploying full electronic health records linking data from all healthcare information systems at once, the government opted for a gradual deployment of the national electronic health record.⁽⁵⁵⁾ However, in 2010 the Dutch government put plans for roll-out of the national electronic health record on hold due to the lack of clinical acceptance, issues surrounding security and privacy, amendments to data protection legislation and uncertainty regarding the type of technology model that was selected.

9.3 Case study: Dutch GP locum summary

There are examples of summary care records in use in the Netherlands. The electronic locum record facilitates a locum GP (mostly when out-of-hours services are being provided) to access a summary of the patient's health information from the patient's GP.⁽⁵⁶⁾

The Twente region was chosen by the Ministry of Health, Welfare and Sports to perform a pilot of the electronic locum record. These regions were chosen because various developments were already ongoing in the field of information exchange. The main aim of this service is to give GPs access to a summary of patient information including;

- health problems
- recent records of the patient's visits to the practice
- current medication
- allergies and intolerances.⁽⁵⁷⁾

In the region of Twente, a patient's medical history can be reviewed when they visit a GP practice and where their own GP is not present. The aim of the service is for GP's to have access to a summary of information instead of allowing access to the medical file itself. This means that the primary owner

¹ In Dutch the electronic record is called the Electronisch Patientdossier

of the medical record is the attending GP. The attending GP sends a locum medical note consisting of a consultation report, medications, activities and specific transfer of data to the primary GP. The primary GP then incorporates the new information into the patient's electronic patient record. The electronic locum record proved to be successful in the Twente region and the adoption of the electronic locum record among GPs was attributed to factors such as clinical leadership and monetary incentives for GPs to undertake the initiative.⁽⁵⁸⁾

10 Summary of findings from Australia, New Zealand and The Netherlands

An overview of the structure of healthcare and the status of eHealth in Australia, New Zealand and The Netherlands is provided below.

- **Australia** has a complex health system that incorporates government states and territories alongside public and private providers. The Australian government funds rather than provides health services. From the countries reviewed, Australia can be viewed as leaders in eHealth with the development of a national My Health Record which is an electronic summary of a person's health information. Individuals can control their own My Health Record and can decide which healthcare provider organizations can access it and what information should be included. The shared health summary (in the form of a clinical document) is uploaded to the My Health Record.
- **New Zealand** The New Zealand Public Health and Disability Act 2000 outlines the structure and funding of public health and disability services. District health boards are responsible for providing or funding the provision of health services in their district. Since 2010, the National Health Information Technology Board has led the development of New Zealand's current electronic health record policy. Information captured at the point of care can be made available to other health professionals and patients via patient and provider portals.⁽⁵⁹⁾ New Zealand has invested significant effort in the area of eHealth and has made good progress on developing interoperability between eHealth systems. However, there is diversity in practices across the various district health boards which can make it difficult to scale from local eHealth solutions to a regional and national level.
- **The Netherlands** introduced major healthcare reform in 2006 and private health insurance became mandatory for all citizens. The provision of health services are the responsibility of private healthcare providers. In 2011, a national electronic health record was rejected by the Dutch parliament due to privacy concerns. In 2011 the Union of Providers for Health Care Communication which included a number of organizations representing GPs, out-of-hours general practice cooperatives, hospitals and pharmacies was set up with responsibility for the exchange of data on the AORTA network. The network stores a patient's GP record. Historically electronic health records were developed at a regional level and are not standardized at national level.

However, almost all general practitioners use an electronic patient record and all hospitals have an electronic health record.⁽⁶⁰⁾

10.1 Summary care records in Australia, New Zealand and The Netherlands

The key characteristics that were identified in relation to the source, content and usage of the summary care records in Australia and New Zealand are illustrated in Table 2 below. In summary, all three countries extract information from GP practice management systems which correlates with the UK who also use GP records as the source of information. There are common categories of information that the three countries use as the core content for their summary care records. This includes, demographics and health identifying information, health problems, medicines, allergies, adverse reactions and immunisations. In addition, New Zealand also include data on laboratory results and recalls and in The Netherlands the electronic locum summary record includes the most recent records of a patient's visit to hospital.

Table 2. Summary of the Australia, New Zealand and The Netherlands

Criteria	Australian Shared Health Summary	New Zealand – regional Compass Summary Care Record	The Netherlands - electronic locum summary record
Population	23.million	4.68 million	17 million
Source	GPs Practice Management System and other healthcare providers where a consultation takes place.	GPs Practice Management System.	GPs Practice Management System.

Core Content	Patient's demographics and health identifying information, current medical condition, medicines, allergies, adverse reactions and immunisations.	Patient's demographics and health identifying information, medicines, problem list (diagnoses, conditions), allergies, immunisations, recalls and laboratory results.	Patient's demographics and health identifying information, health problems, recent records of the patient's visits to the practice, current medication, allergies and intolerances.
Usage	Total number of clinical documents uploaded to the My Health Record system by healthcare providers was 104,983.	45 practices supply information to the Compass summary care record in the Wararapaand Capital and Coast district health board areas. Approximately 80% of patients in those regions have a summary record in the Compass summary care record.	GPs in the Twente region.

10.2 Consent models

There are various consent models used throughout the regions reviewed. In England, there were challenges regarding the issue of consent. Initially, the summary care record in England adopted an implied consent model. However, in June 2010, the British Medical Association voiced strong opposition towards the consent model. In addition, some GPs regarded it as unethical and refused to participate. The clinical content recorded in a patient's summary care record requires the patient's permission before authorized staff can view the information. The aim is that all individuals will have a summary care record unless they 'opt-out' of the programme. Additionally, patients can provide explicit consent to have more specific information captured in the summary care record.⁽⁶¹⁾

Northern Ireland and Scotland have the same consent model for their summary record. This is a two-stage consent model which consists of implied consent for data upload and explicit consent to view their details. This model was popular among all stakeholders. In Wales, a patient has the right to 'opt-out' of the individual health record at any stage.

In Australia, the healthcare provider must obtain the patient's consent and seek consent that they are the individual's nominated healthcare provider. Also, the individual must agree to the healthcare provider creating a shared health summary for the patient which is then uploaded to the My Health Record.

In New Zealand, patients have the option to 'opt-out' of the shared care record and can also choose to withhold specific information. Clinicians are required to seek the patient's permission before they access the shared care record. Importantly, it is the GP's responsibility to inform the patient that their health information will be available to other clinicians who are authorized to use the shared care record. The consent model that was used in relation to the Compass summary care record allows the patient to 'opt-out'. Patients were registered on the Compass summary care record without obtaining their consent, except from the generic consent on their primary health organization enrolment form. However, individuals were given the opportunity to 'opt-out' and were advised they could opt off, and back on, at any time in the future.⁽⁶²⁾

11 Conclusion

Most individuals and clinicians in the countries covered by this review are positive about the concept of a secure summary of key medical information, accessible from wherever the patient requires care.⁽⁶²⁻⁶⁴⁾ However, there are considerations that need to be highlighted as the development of a summary care record requires serious attention around issues such as governance (for example, maintaining continuously updated summary care records), evaluation of their use and appropriate consent models.

Overall, a national summary care record can lead to many benefits for both individuals and clinicians. The quality of care that patients receive can be enhanced by fast, easy access to the relevant patient records. Surveys conducted in Scotland suggest that clinicians working in emergency care value the emergency care record and regard it as a key data source.⁽²³⁾ Summary care records can improve patient experience and patient safety and can empower health professionals by providing consistent, accurate, accessible information to the right person, at the right time in the right location.

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