



Country Brief: Northern Ireland

Authors: D. Whitehouse, U. Walossek, J. Artmann, S. Giest

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About the eHealth Strategies study

The eHealth Strategies study analyses policy development and planning, implementation measures as well as progress achieved with respect to national and regional eHealth solutions in EU and EEA Member States, with emphasis on barriers and enablers beyond technology. The focus is on infrastructure elements and selected solutions emphasised in the European eHealth Action Plan of 2004.

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Reviewer

Brian McKeown

Contact

For further information about this study or the *eHealth Strategies* project, please contact:

		
<p>empirica Gesellschaft für Kommunikations- und Technologieforschung mbH Oxfordstr. 2, 53111 Bonn, Germany Fax: (49-228) 98530-12 info@empirica.com</p>	<p>eHealth Strategies c/o empirica GmbH Oxfordstr. 2, 53111 Bonn, Germany Fax: (49-228) 98530-12 eHStrategies@empirica.com</p>	<p>European Commission DG Information Society and Media, ICT for Health Unit Fax: (32-2) 02-296 01 81 eHealth@ec.europa.eu</p>

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Executive summary

The Northern Ireland Department of Health, Social Services and Public Safety published *Information & Communications Technology Strategy* (March 2005). This document sets out the framework, context and principles of the ICT Strategy. The Strategy was influenced by several earlier papers particularly: *Information and Communications Technology Strategy ICT Strategy Vision Statement* (Draft, June 2001), *Information and Communications Technology Strategy* (July 2002) and *Information and Communications Technology Strategy Management Summary* (June 2002).

In order to consider Northern Ireland's position regarding eHealth interoperability objectives the following eHealth applications have been examined: patient summaries and electronic health records, ePrescription and telemedicine. In overview Northern Ireland's situation is as follows:

In terms of an electronic health record the Northern Ireland Health Minister announced on April 1, 2008, the start of a pilot project to introduce the Northern Ireland Emergency Care Record. The Emergency Care Record is a summary of patient information taken from GP practices. In September 2009, in addition to the Emergency Care Summary project, a pilot project for an Electronic Care Record (ECR) solution provided by Orion was announced, the final evaluation report of which is due by December 2010.

The Electronic Prescribing and Eligibility System (EPES) has been operational since May 1, 2008 throughout Northern Ireland. The system is paper-based and uses two-dimensional barcode technology. In addition to this Northern Ireland now has an electronic history of prescribing and dispensing whereby users can view any of the 16.8 million prescription forms returned annually to the Central Services Agency (CSA).

Several telehealth projects have been piloted in Northern Ireland and many of these then became part of the range of health and social services that are available. The European Centre for Connected Health, which is based in Belfast, has published *Developing a Connected Health and Care Strategy for Northern Ireland Health and Social Care Services* (January 2008). This document outlines the telehealth strategy for Northern Ireland in terms of telemedicine, telecare and remote telemonitoring services. The Minister for Health has set a target that, regionally, 5,000 patients will be able to avail themselves of telehealth monitoring by 2011.

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1 Introduction to the report

1.1 Motivation of the eHealth Strategies study

Following the *Communication* of the European Commission (EC) on “eHealth – making healthcare better for European citizens: An action plan for a European eHealth Area”,¹ Member States of the European Union (EU) have committed themselves to develop and issue national roadmaps – national strategies and plans for the deployment of eHealth applications addressing policy actions identified in the European eHealth Action Plan.

The 2004 *eHealth Action Plan* required the Commission to *regularly monitor* the state of the art in deployment of eHealth, the progress made in agreeing on and updating national eHealth Roadmaps, and to facilitate the exchange of good practices. Furthermore, in December 2006 the EU Competitiveness Council agreed to launch the *Lead Market Initiative*² as a new policy approach aiming at the creation of markets with high economic and social value, in which European companies could develop a globally leading role. Following this impetus, the Roadmap for implementation of the “eHealth Task Force Lead Market Initiative” also identified better coordination and exchange of good practices in eHealth as a way to reduce market fragmentation and lack of interoperability.³

On the more specific aspects of electronic health record (EHR) systems, the recent *EC Recommendation on cross-border interoperability of electronic health record systems*⁴ notes under “Monitoring and Evaluation”, that “in order to ensure monitoring and evaluation of cross-border interoperability of electronic health record systems, Member States should: consider the possibilities for setting up a monitoring observatory for interoperability of electronic health record systems in the Community to monitor, benchmark and assess progress on technical and semantic interoperability for successful implementation of electronic health record systems.” The present study certainly is a contribution to monitoring the progress made in establishing national/regional EHR systems in Member States. It also provides analytical information and support to current efforts by the European Large Scale Pilot (LSP) on cross-border Patient Summary and ePrescription services, the epSOS - European patients Smart Open Services - project.⁵ With the involvement of almost all Member States, its goal is to define and implement a European wide standard for such applications at the interface between national health systems.

Earlier, in line with the requirement to “regularly monitor the state of the art in deployment of eHealth”, the EC already funded a first project to map national eHealth strategies – the eHealth ERA “Towards the establishment of a European eHealth Research Area” (FP6 Coordination Action)⁶ - and a project on “Good eHealth: Study on the exchange of good

¹ European Commission 2004

² European Commission 2007

³ European Communities 2007

⁴ European Commission 2008

⁵ European Patients Smart and Open Services (epSOS)

⁶ eHealth Priorities and Strategies in European Countries 2007

practices in eHealth⁷ mapping good practices in Europe - both of which provided valuable input to the present *eHealth Strategies* work and its reports. Member States' representatives and eHealth stakeholders, e.g. in the context of the *i2010 Subgroup on eHealth* and the annual European High Level eHealth Conferences have underlined the importance of this work and the need to maintain it updated to continue to benefit from it.

This country report on Northern Ireland summarises main findings and an assessment of progress made towards realising key objectives of the eHealth Action Plan. It presents lessons learned from the national eHealth programme, planning and implementation efforts and provides an outlook on future developments.

1.2 Survey methodology

After developing an overall conceptual approach and establishing a comprehensive analytical framework, national level information was collected through a long-standing Europe-wide network of national correspondents commanding an impressive experience in such work. In addition, a handbook containing definitions of key concepts was distributed among the correspondents to guarantee a certain consistency in reporting. For Northern Ireland, Diane Whitehouse provided initial information on policies and initiatives and examples for specific applications which has been further rigorously reviewed. Diane Whitehouse is a former European Commission project officer. She is a partner in The Castlegate Consultancy, a United Kingdom-based policy partnership. Over the 15 years, her work has focused on European policy in eHealth and on ICT use by older adults and persons with disabilities. Relevant information on policy contexts and health system situation, policies and initiatives as well as examples for specific applications was collected by the overall project lead - empirica in Bonn, Germany.

The key tool to collect this information from the correspondents was an online survey template containing six main sections:

- A. National eHealth Strategy
- B. eHealth Implementations
- C. Legal and Regulatory Facilitators
- D. Administrative and Process Support
- E. Financing and Reimbursement Issues
- F. Evaluation

Under each section, specific questions were formulated and combined with free text fields and drop-down menus. The drop-down menus were designed to capture dates and stages of development (planning/implementation/routine operation). In addition, drop-down menus were designed to limit the number of possible answering options, for example with regard to specific telemedicine services or issues included in a strategy document. The overall purpose was to assure as much consistency as reasonably

⁷ European Commission; Information Society and Media Directorate-General 2009

possible when comparing developments in different countries, in spite of the well-known disparity of European national and regional health system structures and services.

Under Section B on eHealth implementation, questions regarding the following applications were formulated: existence and deployment of patient and healthcare provider identifiers, eCards, patient summary, ePrescription, standards as well as telemonitoring and telecare.

The data and information gathering followed a multi-stage approach. In order to create a *baseline* for the progress assessment, the empirica team filled in those parts of the respective questions dealing with the state of affairs about 3 to 4 years ago, thereby drawing on data from earlier eHealth ERA reports, case studies, etc. to the extent meaningfully possible. In the next step, national correspondents respectively partners from the study team filled in the template on recent developments in the healthcare sector of the corresponding country. These results were checked, further improved and validated by independent experts whenever possible.

Progress of eHealth in Northern Ireland is described in chapter 3 of this report in the respective thematic subsections. The graphical illustrations presented there deliberately focus on key items on the progress timeline and cannot reflect all activities undertaken.

This report was subjected to both an internal and an external quality review process. Nevertheless, the document may not fully reflect the real situation and the analysis may not be exhaustive due to focusing on European policy priorities as well as due to limited study resources, and the consequent need for preferentially describing certain activities over others. Also, the views of those who helped to collect, interpret and validate contents may have had an impact.

1.3 Outline

At the outset and as an introduction, the report provides in chapter 2 general background information on the *Northern Irish* healthcare system. It is concerned with the overall system setting, such as decision making bodies, healthcare service providers and health indicator data.

Chapter 3 presents the current situation of selected key eHealth developments based on detailed analyses of available documents and other information by national correspondents and data gathered by them through a well-structured online questionnaire. It touches on issues and challenges around eHealth policy activities, administrative and organisational structure, the deployment of selected eHealth applications, technical aspects of their implementation, legal and regulatory facilitators, financing and reimbursement issues, and finally evaluation results, plans, and activities.

The report finishes with a short outlook.

2 Healthcare system setting

2.1 Country introduction⁸

Northern Ireland is part of the United Kingdom of Great Britain and Northern Ireland. The UK has many different administrative levels and county/council areas. To summarise, **England** has 47 boroughs, 36 counties, 29 London boroughs, 12 cities and boroughs, 10 districts, and 3 royal boroughs. Northern Ireland has 24 districts, 2 cities (excluding Armagh, Newry and Lisburn, which have all city status) and 6 counties. **Scotland** has 32 council areas and **Wales** has 11 county boroughs, 9 counties and 2 cities and counties. Each of the four constituent countries of the United Kingdom has its own, separately administered health service. All are publicly funded and branded as the “National Health Service” (NHS) that offer broadly the same range of services – it is essentially the administrative arrangements in each that are different. The NHS in Northern Ireland is a little different from the other UK health services in that it has a combined health and social care administration: the Northern Ireland Government Department of Health, Social Services and Public Safety.⁹

The box below summarises the key facts about the healthcare situation in the United Kingdom:

Key facts about the healthcare situation in the United Kingdom:¹⁰

Life expectancy at birth: 79.9 years;

Healthcare expenditure as a % of GDP: 8.4% (OECD 2007);

WHO ranking of healthcare systems: rank 18;

Public sector healthcare expenditure as a % of total healthcare expenditure: 82% (OECD 2007).

2.2 Healthcare governance¹¹

In Northern Ireland, the Department of Health, Social Services and Public Safety (DHSSPS) is responsible for overall Health and Social Services policy. Health and Personal Social Services in Northern Ireland are provided as an integrated service. Northern Ireland has reformed its public body structures under what is known as the Reform of Public Administration which resulted in a single Health and Social Services Authority.

In 2004, a National Health Service Reform was introduced in the United Kingdom¹². It included a funding package and resulted in a system reform within the NHS. Individual

⁸ eUser 2005

⁹ eHealth Priorities and Strategies in European Countries 2007

¹⁰ Data from World Health Organization 2000; Health Consumer Powerhouse 2008; World Health Organization 2009

¹¹ Data from: eHealth ERA; empirica and Engineering and Physical Sciences Research Council 2007

¹² Office of Public Sector Information 2004

plans were developed for Scotland, Wales, and Northern Ireland. The goals of the reform included the modernisation of the health infrastructure, increased supply of health professionals, and the definition of national standards.

3 eHealth Strategies survey results

The following sections present the results of the eHealth Strategies country survey. In a first section, the eHealth policy actions undertaken in Northern Ireland are presented. This is followed by a presentation of the administrative and organisational measures undertaken. Section 3.3 presents results on key eHealth applications. Section 3.4 focuses on the technical side of eHealth, namely the role of patient and healthcare provider identifiers and the role of eCards. Legal and regulatory facilitators as well as financing and reimbursement issues are presented in the following chapters, 3.5 and 3.6. The report concludes with evaluation activities (3.7) in the country and an outlook for the future (4).

3.1 eHealth policy action

The eHealth strategies of EU and EEA countries are not always labelled as such. Some countries may indeed publish a policy document which refers to the ICT strategy in the healthcare sector. Other countries such as France and Germany have enshrined the central eHealth activities in legislation governing the healthcare sector. In Germany, the relevant law is the law on the modernisation of healthcare; in France the introduction of an electronic medical record is included in a law concerning social security.

Sometimes, also documents from domains such as eGovernment or Information Society strategies may contain provisions which concern eHealth. In cases where the healthcare system is decentralised, i.e. where power is delegated to the regional level, there may even be strategy documents regarding eHealth from regional authorities.

3.1.1 Current strategy/roadmap

The Northern Ireland Department of Health, Social Services and Public Safety published *Information & Communications Technology Strategy* (March 2005)¹³ after a consultation process that began in 2001. This document sets out the framework, context and principles that guide the ICT Strategy. The implementation of the strategy is described in *HPSS ICT Programme: From Vision to Reality Implementing the ICT Strategy*.¹⁴ The consultation process leading to these publications was informed by several earlier papers by the Northern Ireland Health and Personal Social Services department, namely: *Information and Communications Technology Strategy ICT Strategy Vision Statement* (Draft, June 2001), *Information and Communications Technology Strategy* (July 2002) and *Information and Communications Technology Strategy Management Summary* (June 2002).

¹³ Department of Health 03/2005

¹⁴ Department of Health 03/2005

The 2005 strategy document distinguishes between the need for electronic records and the need for electronic communication.

Electronic Care Records

The electronic care record is intended to contain structured data, text and images generated from a variety of sources and accessible wherever and whenever there is a legitimate need. Access would be managed under a strict “need-to-know” regime complying with agreed rules and procedures for confidentiality and consent.

The strategy assumes that electronic records are likely to offer the greatest benefits, as an essential tool for communication among care professionals, to manage data about individuals and their care, and as a way to enable new patterns of care delivery. The document further notes that at the time of writing (in 2005), “there are elements of electronic care records held in ICT systems in various different locations:

- general practice systems;
- community systems, with more extensive coverage anticipated through:
 - introduction of new Person-centred Community Information Services;
 - hospital systems - patient administration, clinical specialties, pathology;
 - radiology, accident and emergency and others.”

The scale of the Health and Personal Social Services (HPSS) and the use of common systems offer opportunities for an innovative approach to electronic care records. In effect, a virtual electronic care record is created through the combination of various elements: developing care records within all organisations; increasing use of HPSS-wide specialist systems; the consolidation of ICT; the Health and Care Number; and the use of common systems. Developments across the NHS were intended to be reviewed in 2005 when experience of implementing the Integrated Care Records Service became available.

Electronic Care Communications

The 2005 strategy envisaged the following processes as examples suitable for electronic communication:

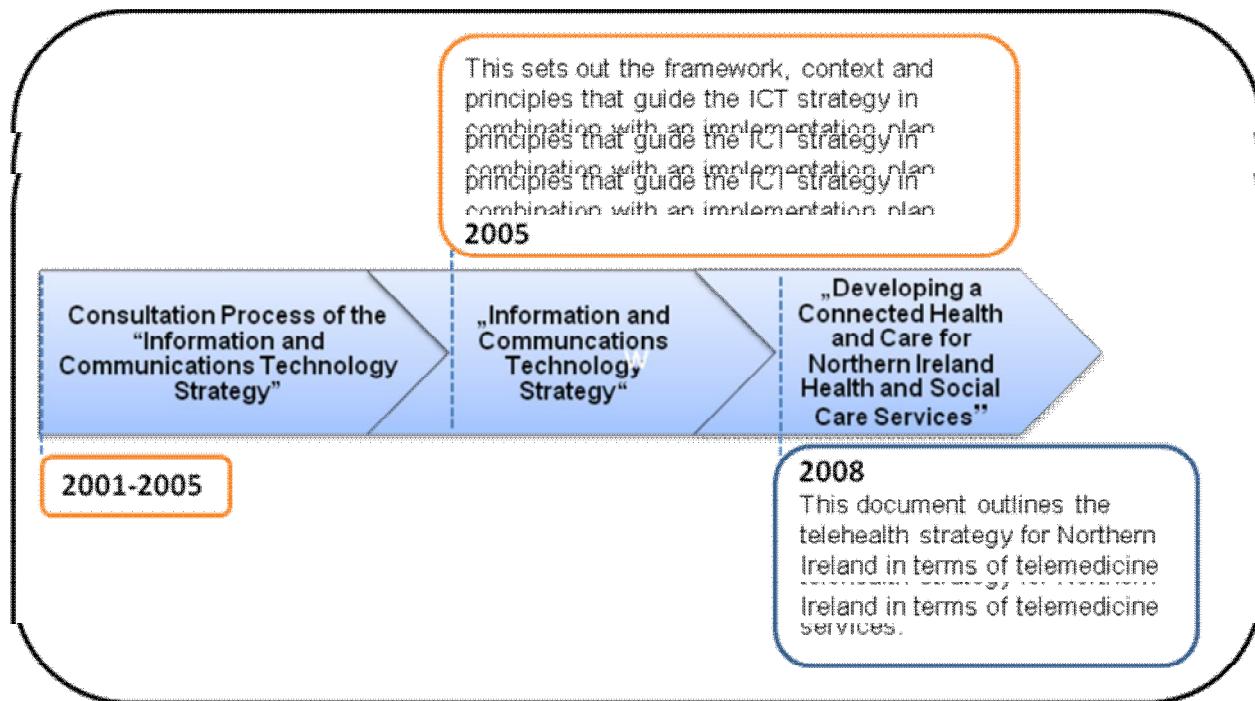
- appointments;
- referrals between care professionals;
- requests for services and communication of the outcome;
- discharge letters and other follow-up communications;
- prescribing.

The strategy envisaged the implementation of new medicines management and stock control systems to provide a basis for subsequent implementation of electronic prescribing. Progress in this area is reported in chapter 3.3.2 of this document.

In addition to the above, the European Centre for Connected Health, which is based in Belfast, published *Developing a Connected Health and Care Strategy for Northern Ireland Health and Social Care Services* in January 2008. This document outlines the telehealth

strategy for Northern Ireland in terms of telemedicine, telecare and remote telemonitoring services.¹⁵

Figure 1: Policy documents related to eHealth in Northern Ireland



3.2 Administrative and organisational structure

Department of Health, Social Services and

The main actor regulating eHealth-related affairs in Northern Ireland is the governmental Department of Health, Social Services and Public Safety. Funding for eHealth is provided through its departmental budget.

ICT Programme Board

Section 6 (pp.125-130) of the Department's 2005 strategy paper¹⁶ described the creation of a Health and Personal Social Services ICT Programme Management Board: "The role of the Programme Board will be to ensure the development of a coherent overall programme of inter-related projects and a realistic timetable for their implementation" (p.127).

In 2005, the Northern Ireland Review of Public Administration found that major reform was required in the administrative structures of health and social services. The subsequent re-organisation created two bodies that each have ICT functions: the Health and Social Care Board and the Business Services Organisation.

Stakeholder views are taken into account via consultations. The Department of Health, Social Services and Public Safety has issued a number of policy documents that are used to plan any consultation process and which seek to involve representative groups and individuals where appropriate.¹⁷ For example, the Chief Medical Officer has issued *Guidance on Strengthening Personal and Public Involvement in Health and Social Care*

¹⁵ European Centre for Connected Health 01/2008

¹⁶ Department of Health 03/2005

¹⁷ Department of Health

(September 2007).¹⁸ This document aims "to assist Health and Social Care (HSC) organisations improve the quality and effectiveness of user and public involvement as an integral part of good governance arrangements and to support the development of a more patient and user-centred HSC envisaged by the reform programme" (section 1.1).

3.3 Deployment of eHealth applications

3.3.1 Patient summary and electronic health record (EHR)

In this study, the epSOS project's definition¹⁹ of a patient summary was used as a general guideline. There a patient summary is defined as a minimum set of a patient's data which would provide a health professional with essential information needed in case of unexpected or unscheduled care (e.g. emergency, accident), but also in case of planned care (e.g. after a relocation, cross-organisational care path).

Lacking a standard definition, a patient's electronic health record (EHR) is here understood as an integrated or also interlinked (virtual) record of ALL his/her health-related data independent of when, where and by whom the data were recorded. In other words, it is an account of his diverse encounters with the health system as recorded in patient or medical records (EPR or EMR) maintained by various providers like GP, specialists, hospitals, laboratories, pharmacies etc. Such records may contain a patient summary as a subset. As of yet, fully-fledged EHR systems rarely exist, e.g. in regional health systems like Andalucia in Spain or Kronoberg in Sweden, or in HMOs (health maintenance organisations) like Kaiser Permanente in the USA.

It should be noted that in most policy documents reference is made simply to an "EHR" without any explanation of what is meant by it, thereby in reality even a single, basic electronic clinical record of a few recent health data may qualify. As a consequence, this section can only report on national activities connected to this wide variety of health-related records without being able to clearly pinpoint what (final) development stage is actually aimed for or has been reached so far.

Northern Ireland Emergency Care Record pilot

On April 1, 2008, the Northern Ireland Health Minister announced the start of a pilot project to introduce the Northern Ireland Emergency Care Record.²⁰ The Emergency Care Record is a summary of patient information taken from GP practices. It includes the patient's date of birth and gender; the patient's address and phone number; and the patient's current medication and any known allergies. If the pilot testing is successful, it will be rolled out across the rest of Northern Ireland. This emergency care record is based on the emergency care record system in Scotland. Currently, activities in Northern Ireland focus on the transfer of the agreed data-set to the ECR repository and the validation of these data.

In September 2009, in addition to the Emergency Care Summary project, there was an announcement of a proof-of-concept pilot project for an Electronic Care Record (ECR) solution provided by Orion. Two hospitals and two GP surgeries across two of the five

¹⁸ Safety Quality & Standards Directorate Office of the Chief Medical Officer 09/2007

¹⁹ European Patients Smart Open Services

²⁰ Northern Ireland Executive 2010; eHealth Insider 2008

Health and Social Care Trusts began to share medical records and basic social care information using the Concerto Portal from Orion Health. "The one-year deal will be to develop a new portal-based electronic health record, predominantly for use in secondary care but linking hospitals and practices, with the potential to also link social care.²¹" The web-based portal would aggregate information "in real time from more than ten systems, including Patient Administration Systems, laboratory, radiology, A&E, GP and the health and care index".²² It was expected that the project would run from March 2010, and that it would be evaluated three to six months afterwards with a view to potential national rollout.²³ Preliminary evaluation results from the pilot sites suggest that the system is increasingly used by a number of clinicians on a daily basis. The final evaluation report on the project is due in December 2010.

Only indications of broad challenges can be offered as very little publicly available information about the individual projects has been found. The five main challenges are:

- uncertainty of funding;
- inadequate training or insufficient preparation for changes to jobs and work organisation;
- delivery of hardware or software that is inappropriate or offers too little functionality;
- late delivery of hardware or software;
- lack of support from healthcare professionals and patients.

3.3.2 ePrescription

In the framework of this study and following work in epSOS²⁴, ePrescription is understood as the process of the electronic transfer of a prescription by a healthcare provider to a pharmacy for retrieval of the drug by the patient. In this strict sense, only few European countries can claim to have implemented a fully operational ePrescription service.

The Electronic Prescribing and Eligibility System (EPES)²⁵ has been operational since May 1, 2008 throughout Northern Ireland. The system is paper-based and uses two-dimensional barcode technology. Northern Ireland Health and Social Care now has at its disposal a single, patient-centred, electronic history of prescribing and dispensing, and the ability to call up electronically and view each of the 16.8 million prescription forms returned annually to the Central Services Agency (CSA). This electronic system replaces the previous paper-based manual handling systems on which Northern Ireland was previously dependent.

The system has been implemented and is in use. A useful discussion of the other options - and challenges - that had been considered at the beginning of the project can be found in *Benefits of a Northern Ireland Electronic Prescribing and Eligibility System (EPES): A*

²¹ eHealth Insider: Bruce S. and Hoeksma J. 2009

²² eHealth Europe: Hoeksma J. 2009

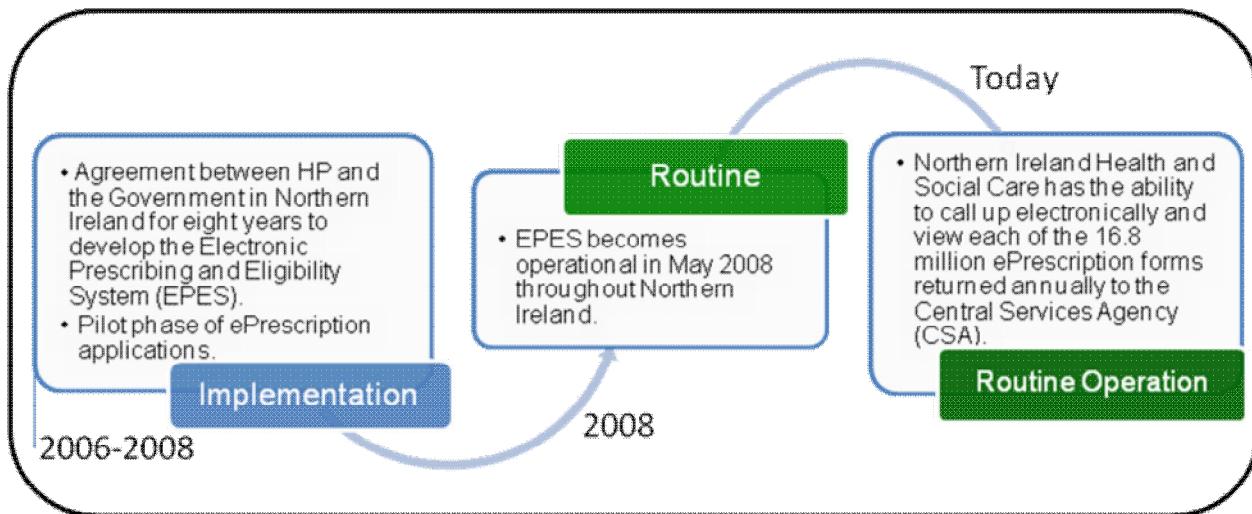
²³ Southern Health & Social Care Trust 2008

²⁴ European Patients Smart and Open Services (epSOS)

²⁵ Davis 2008; Barr 2008

Comparison with the UK Electronic Transfer of Prescriptions (ETP). It was written by the then EPES project manager and published on 16 December 2005.²⁶

Figure 2: ePrescription progress in Northern Ireland



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3.3.3 Telemedicine

The use of telemedicine applications is recognised as beneficial to enable access to care from a distance and to reduce the number of GP visits or even inpatient admissions. Commission services define telemedicine as “the delivery of healthcare services through the use of Information and Communication Technologies (ICT) in a situation where the actors are not at the same location”²⁷. In its recent communication on telemedicine for the benefit of patients, healthcare systems and society, the Commission re-emphasises the value of this technology for health system efficiency and the improvement of healthcare delivery²⁸.

Several telehealth projects have been piloted in Northern Ireland and many of these then became part of the range of health and social services that are available. There appears to be little publicly available information for national initiatives, but the regional Health and Social Care Trusts (i.e., these are different regions in Northern Ireland) include details of local or regional projects in their own annual reports and regional strategy documents.²⁹

The European Centre for Connected Health, which is based in Belfast, has published *Developing a Connected Health and Care Strategy for Northern Ireland Health and Social Care Services* (January 2008). This document outlines the telehealth strategy for Northern Ireland in terms of telemedicine, telecare and remote telemonitoring services.

²⁶ Davis 2005

²⁷ Europe's Information Society

²⁸ European Commission 2008

²⁹ South Eastern Health and Social Care Trust 2008/2009;South Eastern Health and Social Care Trust 2008

Regional strategies are also issued which describe plans to deploy telehealth solutions to provide new or improved services.

The South Eastern Health and Social Care Trust has been working in partnership with the European Centre for Connected Health to develop telehealth and a remote telehealth monitoring service. This is a new programme that enables people with chronic diseases to receive remote monitoring which helps keep them as well as possible, for as long as possible, and reduces the risk of their hospital admission. It helps specialist nurses and doctors to keep a closer check on the health of their patients. Patients who are in receipt of this service are usually on the programme for a 12-week cycle of care. They have equipment in their home to measure their key vital signs, for example, electronic scales, a blood pressure cuff, and a blood glucose meter. The readings from the equipment are sent via a phone line to a central computer. The measurements are analysed. Where a problem is detected, a nurse contacts the patient so that early care can be given. The three disease areas which are being monitored within the programme are Chronic Obstructive Pulmonary Disease (COPD), Diabetes, and Congestive Heart Failure (CHF).

By the end of March 2009:

- 150 COPD patients received 12 weeks of telehealth home monitoring
- 48 Diabetic patients received 12 weeks of telehealth home monitoring with a further 100 patients receiving mobile telemonitoring through the Di@l-log service currently offered by the Ulster hospital
- 20 CHF patients received 12 weeks of telehealth home monitoring.

The Minister for Health has set a target that, regionally, 5,000 patients will be able to avail themselves of telehealth monitoring by 2011. The Trust is well on target to ensure that more than 900 local patients will benefit each year. The COPD service has been recognised by receiving the Nurse of the Year Award (from the Royal College of Nurses) and the Northern Ireland Health Care Award.³⁰

There is no specific accreditation given for health professionals who are involved in the provision of telemedicine services to patients. Although continuing education in general is strongly promoted by all the regulatory bodies in the UK that govern health professionals in Northern Ireland.

3.4 Technical aspects of implementation

A key prerequisite for the establishment of an eHealth infrastructure is the ability to uniquely identify citizens/patients and healthcare professionals. This part of the survey deals with identifiers and how they are stored. This section does not deal with the tokens through which identification can or will take place. One such possibility would be via an eCard. This topic is dealt with in the following section. The current section focuses solely on whether or not unique identifiers are in place in Northern Ireland and for which purpose.

³⁰ Annual Report and Accounts 2008/09, op. cit.

3.4.1 Unique identification of patients

In the *Information and Communications Technology Strategy* (July 2002), the Department of Health and Personal Social Services (HPSS) noted the need for a unique identifier within the HPSS for all users of health and care services (p.49). This is followed by a brief description of the Unique Patient and Client Identifier project. This project had been established (in 2003) to implement the new identifier, known as the Health and Care Number (HCN), across all systems in the HPSS. The HCN has been fully operational in Northern Ireland since April 2008. Current efforts focus on further improvements to the infrastructure that hosts the HCN service. On an organisational level, any problems arising from data quality issues and duplicates in patient registrations are now being addressed. Teams of specialists are working on understanding how workflows can be improved in order to avoid any challenges to data quality.

3.4.2 Unique identification of healthcare professionals

No eCard for citizens or healthcare professionals exists in Northern Ireland. There is no publicly available information that the Northern Ireland Assembly or the Department of Health Social Services and Personal Safety is considering the introduction of eCards. The 2005 ICT strategy had identified the need for "to establish a secure method of identifying and authenticating staff involved in accessing or communicating care information." It is unclear from currently available information, how far this project has matured.

3.4.3 Standards

Standards are not only crucial to enable interoperable exchange of meaningful information in the healthcare system; they also ensure secure access to patient records by healthcare providers and citizens. This study aims to identify, among other usage, standards related to the domain of health informatics, such as the SNOMED Clinical Terms or the LOINC terminology.

The United Kingdom is a member of the International Health Terminology Standards Development Organisation (IHTSDO). No publicly available information has been found regarding the adoption or use of further specific international health informatics standards in Northern Ireland. However, it is likely that international informatics standards are in use: at least one system, the Emergency Care Record (see section 3.3.1) is based on the Scottish equivalent record which is known to use such standards.

The Northern Ireland Department of Health Social Services and Public Safety has published a document, *Information and Communication Technology Standards* (January 2009) that refers to other standards documents that are used by the National Health Service in England.

3.5 Legal and regulatory facilitators

Legal and regulatory issues are among the most challenging aspects of eHealth: privacy and confidentiality, liability and data-protection all need to be addressed in order to make eHealth applications possible. Rarely does a country have a coherent set of laws specifically designed to address eHealth. Instead, the eHealth phenomenon has to be addressed within the existing laws on professional liability, data protection etc.

3.5.1 Patient rights

The announcement of the introduction of the Emergency Care Record included the following statement:

"Patients will be asked for their explicit consent to access their record each time they are being treated by the GP Out of Hours service."³¹

The Department of Health, Social Services and Public Safety has issued the *Code of Practice on Protecting the Confidentiality of Service User Information* (January 2009). This document addresses patient access rights and confidentiality issues from the perspective of the healthcare professional:

"individuals have a right to control access to and the disclosure of their own health and social care information by giving, withholding or withdrawing consent" (Preface, p.4)

The *Records Management Policy* (February 2010), issued by the Health and Social Care Business Services Organisation, provides a code of conduct regarding records from the perspective of the information and communications technology professional.³²

The *Code of Practice on Protecting the Confidentiality of Service User Information* (January 2009)³³ issued by the Department of Health, Social Services and Public Safety considers different circumstances when situations with relevance to confidentiality might occur³⁴. Appendix 1 and Appendix 2 of this code of practice discuss the issues of confidentiality and disclosure with respect to the relevant legislation.

Access to, and information about, government services in Northern Ireland is available to citizens online through NIDirect. *Accessing Medical Records* describes how to apply in writing to obtain a copy of one's medical records. There is no information here regarding what, if any, information can be added by a patient to existing medical records.

With regard to accessing someone else's medical information, the entry for Accessing Medical Records advises: "If you are applying for medical records on behalf of someone else, you will need their consent or a power of attorney."³⁵

Furthermore, the *Code of Practice on Protecting the Confidentiality of Service User Information* (January 2009) issued by the Department of Health, Social Services and Public Safety states that patients should be advised of "their rights to access and where

³¹ Northern Ireland Executive 2010

³² Department of Health Social Services and Public Safety 2009; Business Services Organisation 2010

³³ Department of Health Social Services and Public Safety 2009

³⁴ See sections 3.11 3.12 and 4.7 of the code.

³⁵ nidirect Government Services 2010

Use of record data

necessary to correct the information held about them within health and/or social care records.".³⁶

In general, any use of record data requires the consent of the health service user. However, there may be situations and purposes which override this general rule. These are also laid down in the *Code of Practice* which states: "when the purpose of a use or disclosure relates to health and social care, but is not directly for the care of that service user, the express consent of that service user is usually required. The possible exceptions to this requirement for consent are where a statute, court or tribunal imposes a requirement to disclosure or there is an overriding public interest in the use or disclosure" (section 3.16, p.15)

Section 3.17 of the document outlines the principles for good practice regarding the disclosure and use of information for secondary purposes, including the need to anonymise or pseudonymise the data (see also sections 2.16 - 2.19 of the code for a discussion of these terms). Section 3.18 addresses those situations where it is impractical to obtain service user consent but where there are clear public health and social care interests.

Sections 3.19-3.27 deal at length with those occasions where it is "legally and ethically acceptable to use or disclose service user information for purposes which are neither for the direct care of that service user nor for a secondary health and social care purpose." Examples include the prevention of serious harm to third parties, child protection, prevention of terrorism, and prevention, detection or prosecution of a serious crime.

The, sometimes conflicting, interests of the patient and public health purposes for data are illustrated in an example shown in the 2010-2011 business plan of the Northern Ireland Cancer Registry. GPs need to ask for explicit consent from cancer patients to obtain the identifiable medical records that the Registry says it needs to have in order to do its work. Examples of such data include longitudinal research and the identification of tendencies towards cancer within families. However, GPs may find it inappropriate to impose a further burden on patients, by asking for their consent in this case,, in addition to delivering the bad news to them with regard to the announcement about cancer. Hence, a lot of useful data may remain unavailable.³⁷

The Registry argues that, if legislation were in place to declare cancer - or a few specific cancers - to be notifiable diseases, these data could be gathered under a "public health" classification that would, as a result, override the need to obtain patient consent.

³⁶ Department of Health Social Services and Public Safety 2009, section 2.4, p.7

³⁷ Department of Health Social Services and Public Safety 2009;Department of Health Social Services and Public Safety 2006

3.6 Financing and reimbursement issues

The Department of Health, Social Services and Personal Safety is the main funding source for national and regional eHealth infrastructure.

The annual budget for the Department of Health, Social Services and Public Safety is approximately £4 billion. No publicly available information has been found that shows details of annual funding allocated to eHealth in Northern Ireland.

Section 7 of the *Information and Communications Technology Strategy* (March 2005) describes the overall funding of the programme. It estimates £110-120 million over eight years and recurring annual costs of about £15 million. Section 5.9 (pp.98-124) of the same document provides a more detailed breakdown of the major components of the Programme; all estimates are at 2005 values.

In October 2008, the Health Minister announced an investment of £55 million "in capital over the next three years" to ensure that additional information technology is available across health and social care. "This funding is part of a total planned investment of £300million over the next ten years for Information and Communication Technology". The announcement contains only broad descriptions of where the funds will be invested. No publicly available information was found that contains more specific details of the investment.³⁸

Northern Ireland receives EU Structural Funds under the EU Cohesion Policy (2007-2013 funding round). The funds are allocated from the European Sustainable Competitiveness Programme and the European Social Fund Programme.

The European Commission Northern Periphery Programme contributes to the funding for the telecare/telehealth research project, *MyHealth@Age*.

The main challenge to financing eHealth in Northern Ireland is the imminent reduction in public sector spending due to the fiscal deficit. A secondary issue is the possibility of changes to, or replacement of, the Barnett Formula. This is the mechanism used by the United Kingdom Treasury to determine the annual block grant for Northern Ireland, Scotland and Wales. Several shortcomings of the formula have been pointed out, and the House of Lords Barnett Formula Select Committee has recommended that it should be replaced. Any change to the funding formula will not necessarily benefit Northern Ireland.

Reductions or delays to funding some projects might also have the effect of making them uneconomic investments.³⁹

³⁸ Department of Health Social Services and Public Safety 2007; Northern Ireland Programme for Government and Budget 2008; Northern Ireland Executive 2010; Department of Health Social Services and Public Safety 2008

³⁹ Twigger 1998; Institute for Public Policy Research 2010; Northern Ireland Assembly 2007; Parliament UK

3.7 Evaluation results/plans/activities

From a public policy perspective, evaluation is a key activity in the policy-cycle. It provides insights into the success or failure of a policy or project and leads to new policy goals and new methods of implementation. The need for evaluation of eHealth policies and projects has been stressed time and again by the EC, not least in order to further the spread of eHealth in the process of healthcare delivery.

Although so far no public information is available on any actual evaluation which has been conducted in Northern Ireland regarding the emergency care record projects or other eHealth efforts, an evaluation of the currently rolled-out Electronic Patient Record Project mentioned above, is planned. In addition, some theoretical groundwork has been published.

The Northern Ireland Department of Finance and Personnel has prepared guidelines to be used to appraise policies and programmes; to implement, manage, monitor and evaluate monitor projects; and to prepare business cases.⁴⁰

Within the Department of Health, Social Services and Public Safety, the focus appears to be on business cases. Departmental economists "review Business Cases submitted to the Department from Trusts, Boards and Health Care Organisations to ensure high standards in terms of quality, accountability and Value for Money."⁴¹ Advice from departmental economists can also be obtained prior to the submission of a business case. The economists use guidelines provided by the Northern Ireland Department of Finance and Personnel and by the United Kingdom Treasury.

4 Outlook

In terms of electronic healthcare records the outlook is good. The preliminary evaluation results from the pilot sites of the pilot project for an Electronic Care Record (ECR) suggest that the system is increasingly used by a number of clinicians on a daily basis. The final evaluation report on the project is due in December 2010.

The future is also promising for Telemonitoring: the Minister for Health has set a target that, regionally, 5,000 patients will be able to avail themselves of telehealth monitoring by 2011. The Trust is well on target to ensure that more than 900 local patients will benefit each year.

For eCards progress is needed for the establishment of a secure method of identifying and authenticating staff involved in accessing or communicating care information. In terms of patients efforts will focus on further improvements to the infrastructure that hosts the HCN service. No eCard for patients is planned yet.

Overall, the progress of eHealth will face the challenge of the imminent reduction in public sector spending due to the fiscal deficit. The extent of this effect, however, remains to be seen.

⁴⁰ Department of Finance and Personnel

⁴¹ Department of Health Social Services and Public Safety

5 List of Abbreviations

A&E	Accident and Emergency
CHF	Congestive Heart Failure
COPD	Chronic Obstructive Pulmonary Disease
CSA	Central Services Agency
DHSSPS	Department of Health, Social Services and Public Safety
DRG	Diagnosis Related Group
EC	European Commission
ECR	Electronic Care Record
EEA	European Economic Area
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPES	Electronic Prescribing and Eligibility System
EPR	Electronic Patient Record
epSOS	European patients Smart Open Services
ERA	European Research Area
ETP	Electronic Transfer of Prescriptions
EU	European Union
GDP	Gross Domestic Product
GP	General Practitioner
HCN	Health and Care Number
HCP	Healthcare Provider
HL7	Health Level Seven International (authority on standards for interoperability)
HPC	Health Professional Card
HPSS	Health and Personal Social Services
HSC	Health and Social Care
ICT	Information and Communication Technology
ID	Identification (e.g. number, card or code)
IHTSDO	International Health Terminology Standards Development Organisation
IT	Information Technology

LSP	LSP- Large Scale Pilot
OECD	Organisation for Economic Co-operation and Development
PHS	Personal Health System
R&D	Research and Development
UK	United Kingdom
WHO	World Health Organization

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