National IT strategies – Denmark, England and Canada

National Information Structure Strategic Planning
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Summary

The purpose of this document is to present some of the external environment monitoring that is carried out within Socialstyrelsen's 'National Information Structure' project (NI). The aim is to present a summarised comparison of the substance of the national IT strategies of Denmark, England and Canada, as well as the approach that the various countries use in their implementation. Particular emphasis has been placed on highlighting how national information structures are managed in that context.

Using existing IT strategies from Denmark, England and Canada, and the official project sites from associated implementation projects as a starting point, a literature compilation was made. This was then complemented by a search through scientific publications and EU projects.

Individual interviews were carried out with selected researchers who have an insight into the ongoing national projects.

In short, we can establish that Denmark has chosen a solution whereby existing IT systems are retained, and has developed the MedCom standard for message handling between the systems. England has concentrated on a central solution where the same system is used by everyone. The NHS development, however, demonstrates shortcomings when it comes to user involvement and, above all, the British Medical Association is very sceptical about the results. Canada is focusing on common standards and architectures for interoperability, whilst the development of individual IT systems is done at the local/regional level.

It is difficult to get adequately detailed information. Neither Denmark, England nor Canada appear to currently have a direct equivalent to the NI project. When it comes to processes, one usually works with sub processes in connection with compiling the technical architecture, but we have not found a comprehensive process description. As far as the technical architecture goes, it seems that both HIAl (Canada) and SPINE (England) use HL7 version 3 for message transferring, and even Denmark is discussing a project for mapping MedCom to HL7 v3 in a recently published proposal.

It is difficult to find clear success factors for national implementations. No one feels that they have genuinely succeeded in fully carrying out their ideas and plans for a national IT implementation within the healthcare sector. The problems appear to be similar in many countries, namely:

- Difficulties in getting a large number of different parties in agreement;
- Difficulties in defining a common infrastructure for many different purposes;
- Difficulties in implementation within the clinical environment.

Experiences from other countries and descriptions in the literature indicate that there are nevertheless some factors that seem to contribute to a more successful implementation. As such, the following can be discerned:
• Clear responsibility
• User involvement
• Use of standards and standard terminology
• Risk analysis and assessment

These experiences from other countries show that, in addition to clear mandates and decisions, compliance to the standards at the national level and local responsibility when it comes to the actual technical implementation; an initiation process is needed that takes the local circumstances into consideration.

As far as Sweden is concerned, the recommendation is to especially look at the countries that have a similar health care system to its own, such as Canada, Spain, Italy, Holland and New Zealand.

It can also be stated that most countries appear to have the same kind of problems and that Sweden has come a long way when compared with other countries. However, it seems important for Sweden (and for the NI project) that the national projects are clearly coordinated and, consequently, to have distinct mandates and clear responsibility distribution.
Introduction

The purpose of this document is to present some of the external environment monitoring that is carried out within Socialstyrelsen's 'National Information Structure' project (NI). The aim is to present a summarised comparison of the substance of the national IT strategies of Denmark, England and Canada, as well as the approach that the various countries use in their implementation. Particular emphasis has been placed on highlighting how national information structures are managed in that context.

Background

Based on national IT strategies in various countries, great efforts are under way to bring about a working, comprehensive IT structure for healthcare. It is important for the NI project to benefit from the experiences from those countries, but also to get a picture of how Sweden compares internationally.

This investigation is intended as the start of a comparative, longitudinal study of the development and implementation of national information structures in a number of different countries.

The longitudinal study aims to map out how various countries have addressed the problem as well as what factors affect decisions and the result, and in what manner.

The 'National Information Structure' (NI) project

The national information structure is about healthcare and is a description of the type of information that is needed for good care giving, where cooperation, follow-ups, systematic improvements, open reports, performance and comparisons are kept in focus. The structure will be described in terms of healthcare processes and is applied to Swedish health care.

The national information structure is based on good healthcare according to the legislator's intentions and the goals that are set up by the national IT strategy for health care.

The national information structure should include 'the essence' of healthcare documentation; that is, the essential information that follows the individual (the patient/user) through the healthcare process (through time or geographical location). Further, the structure should be sustainable in the long-term, suitable and satisfy formal requirements. Thus, it does not need to include all of the available information – just the essence of the kind of information that will be included in suitable healthcare documentation.

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Demarcations

In the initial stage, the result of which is described in this document, the comparison will be made based solely on literature studies and conversations with selected persons. The document is intended as a support document to the NI project, and claims neither to paint a complete picture nor to give a scientific analysis.
Method

Using existing IT strategies from Denmark, England and Canada, and the official project sites from associated implementation projects as a starting point, a literature compilation was made. This was then complemented by a search through scientific publications and EU projects.

Individual interviews were carried out with selected researchers who have an insight into the ongoing national projects.
Results

The European perspective
Developing the 'European eHealth Action Plan' in 2004\(^2\) resulted in the European member states developing national IT strategies. Only a few countries, such as Denmark, Finland and Norway, started to develop IT strategies before then – as early as the 1990s.

Establishment and responsibility
In two thirds of European lands, the introduction of IT systems is directly linked to the goals of national health policies.

In ten countries, eHealth is a central part of comprehensive healthcare strategies.

14 lands have more focused goals (cost effectiveness, quality of care) and in 13 countries, eHealth is one of many points under national IT development, or part of a public e-service strategy.

Responsibility distribution for IT strategies differs between the lands:
1. Under the jurisdiction of the Ministry of Health, e.g. Austria, France, Latvia, Lithuania, Luxembourg and Poland;
2. Distributed responsibility, e.g. Estonia, Ireland, Italy, Hungary and the Netherlands.

The need for an agreed national strategy is generally clearer in countries with federative organisations (e.g. Austria), decentralised health and medical care systems (e.g. Finland and Spain) or where more than one ministry is involved (e.g. Belgium and Italy).

Many countries have established some kind of consultation/competence unit that lies under the jurisdiction of responsible ministries. The unit's role can be to develop, review and follow up the country's strategic goals, and/or to implement and manage eHealth infrastructures and projects.

Finland and Luxembourg have, for example, national eHealth advisory panels. Austria and Turkey have thematic work groups with specific assignments. Slovakia has an eHealth 'think-tank'. Germany has a national organisation called 'Gematik' which received a legislated national responsibility. In Great Britain, NHS Connecting for Health – under the Department of Health – is responsible for the implementation of the national IT program (NPfIT).

Priorities and goals
In about half of the countries mentioned in the ERA Fact Sheets, various short and long-term priorities are detailed. IT strategy priorities cover a wide spectrum: from the introduction of individual applications to the construction of national eHealth infrastructures by interconnecting existing applications and systems and setting up comprehensive electronic medical record systems.

Specific goals involve the introduction of electronic cards, other methods for identifying patients and web portals for patients, citizens and healthcare practitioners. A great deal of attention is given to standards for interoperability (technical and semantical) as well as legislation and the legal framework.

Unsurprisingly, many of the priorities mentioned in the EU Action plan reappear in national IT strategies.

On the other hand, issues concerning public healthcare and training for the eHealth system are hardly mentioned (with the exception of France). Even economic and socio-economic aspects, such as efficiency, sustainability and change management are not explicitly mentioned.

Since the development of eHealth brings risks along with the benefits, a review of the legal framework is absolutely necessary in order to minimise the risks and to protect the populace.

Several countries have started the process when it comes to patient rights (e.g. Belgium), confidentiality (e.g. Belgium and Ireland), certification of EPR software (Electronic Patient Records – e.g. Belgium), public information (e.g. Estonia), and digital signatures (e.g. The Czech Republic, Estonia, Latvia, Lithuania, Poland and England).

Implementation and content
Development and implementation are under way in many countries. The subsequent (project) areas can be grouped in this as follows:

Infrastructure
'Infrastructure' in most publications means a technical communications and network solution – a structure that allows technical and semantic interoperability and technical security solutions. It also means an organisational infrastructure with appropriate legislation and legal framework. In most cases, however, the main focus is aimed at a technical communications solution.

Examples:
Sjunet (Sweden), MedCom (Denmark), messaging systems on a common infrastructure (Norway), interconnection of regional networks (Finland).

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Patient record systems

Most countries intend to develop some kind of summary care record; that is, a defined set of data that is exchanged across professional and organisational boundaries (e.g. Germany, Sweden and Turkey).

Some countries are even endeavouring to develop a 'life-long or detailed care record' – a comprehensive journal system that follows the patient.

Many countries have existing electronic patient record systems (mainly in hospitals, but also in primary healthcare) that cannot exchange data with each other. National record systems are most often found only partly implemented. For example, Luxembourg has a radiological system and Sweden has a national electronic prescriptions solution.

Spain is developing its system on a regional basis (e.g. Andalusia). Only one country, The Czech Republic, has a full national implementation. Denmark plans to expand its MedCom infrastructure with message handling in order to include a national patient records solution.

Mobility for patients and nursing staff

Projects relating to this area focus mainly on e-identification and electronic cards. A lot of activity is under way in Germany, the Netherlands and Belgium.

Legislation and legal framework

Apart from existing legislation on data security, confidentiality, patient safety, etc., some lands are working on creating specific guidelines for eHealth; for example, medical confidentiality and data ownership (France), electronic prescriptions (Finland), legal framework for medical informatics standards (France), and medical informatics (Austria).

Follow-up and assessment

Only six countries report existing (Ireland and England) or planned (France, Slovenia, Slovakia and Bulgaria) activities for follow-up and assessment.

Denmark

National strategy – history

1996 – Strategy for the implementation of electronic patient records

In December 2007, a new version of the Danish strategy was launched, 'Digitalisering af sundhedsvaesenet' (Digitalisation of the Danish Healthcare

4 European Research Area (ERA) – Fact sheet, Denmark:
Service), which applies between 2008 and 2012. The strategy identifies a new initiative and common direction, and builds upon good practices and existing solutions around the country. The realisation of the national healthcare strategy is described in a list of precise action plans that are developed and updated on a regular basis:

3. Better cooperation through leadership, direction and coordination.
5. Gradual progress towards consistency between local solutions.
6. Foreseeable projects and needs-based development.
7. IT for the entire healthcare sector.
8. Making use of the international dimension.
9. Continued development and application in the long term.

The national approach will concentrate on the development of a common infrastructure, the establishment of a number of common services and pinpointing a set of minimum requirements that must be fulfilled by its operators. The aim of a common infrastructure is to create a digital link that opens up the possibility to exchange data across the entire healthcare spectrum. The infrastructure is comprised of a national IT architecture, an upgraded healthcare computer network, standards for communication within the healthcare system and a national solution for security. Two high priority national services that will be developed are: a common medical card that provides up-to-date information on the relevant medication, and a national patient desk that makes data from a hospital's PAS and EP systems available to other hospitals, practising doctors and the populace.

Regions and municipalities will soon focus on strengthening, developing and implementing existing solutions. At the same time, local solutions will start to apply the national common requirements, which also apply to private healthcare services5.

**Purpose and Aims**

The driving principle of the Danish strategy is that 'shared information is the basis for uninterrupted healthcare and patient involvement.' The strategic goals are:

- High quality of care
- Straight answers
- Shorter waiting times
- High degree of user satisfaction
- Better information on service and quality
- Efficient use of resources
- Freedom of choice

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Contents – project (of interest to NI)

- Electronic patient records
- Basic structures (conceptual process model, reference information model for information retrieval and exchange)
- Clinical content (SNOMED CT/SNOMED Allied Standards)

England

National strategy – history

2002 – National Programme for IT (NPfIT)

Along with Scotland, Wales and Northern Ireland, England has the National Health Service (NHS), which receives public financing and supplies similar care for all four countries. Administration is taken care of separately for each country, so there are four IT strategies.

Contents – project (of interest to NI)

Electronic patient records

- NHS Care Records Service (NHS CRS) consists of the Summary Care Record (SCR), the Detailed Care Record (DCR) and the Secondary Uses Service (SUS) for statistical assessments. (Annex 2)

England used to have great plans to measure effects and follow up and manage patient centred care in the form of a DCR, but that goal has since been rejected, so the only thing that remains is an SCR, which stores information on allergies and some medical prescriptions.

Implementation of SCR has been delayed and it is operated only in the form of test installations at some locations. One can choose to 'opt-out' of the consent management solution for SCR, or 'opt-in' to expand SCR with further clinical information. Consent management has, however, been poorly communicated to the patients and healthcare staff. A number of planned features are yet to be implemented. Security is seen as a challenge, and a careful assessment as well as user training is recommended.

As for DCR, it is unclear as to when it will be ready. Its specifications are relatively unclear. Insufficient user involvement is seen as the main reason for DCR's failure. In the future, it is recommended that more responsibility is given locally for how the system should be formulated, but at the same time to require compliance with the standards that are implemented nationally instead of attempting to control technical implementation locally. The institution of a standardisation body and a clear timetable for the introduction of SNOMED CT is recommended.

Although the centralised approach of the NHS has had its advantages, clear objectives are now needed along with precise timetables and a more
decentralised approach that assures that the local organisations take their responsibility for the introduction process.

Canada
National strategy – history
The development of Canada's 'health infostructure' has been relatively fast. It took just two years from the earliest recommendations until the federal states accepted the recommendation to develop a national health information plan. In August 1997, the Ministry of Health established the Advisory Council on Health Infostructure (1997-1999), which was commissioned to present a final report within 18 months.

The report confirmed that the setting up of a national health information plan would lead to a significant improvement in the quality, access and efficiency of health services in Canada. The advisory council's four goals included developing a plan for Canada's health information system and identifying important requisites.

In addition, a federal plan for implementing the most important system components and proposing a common motion for achieving a Canadian consensus of opinion and an integrated health information system also identifies questions, challenges and obstacles, and recommends possible solutions. Infoway was set up in 2001 to support and speed up the development and implementation of effective, interoperable electronic health solutions, and define and recommend data control standards that assure comparability in the health information network.

Contents – project (of interest to NI)
Interoperable EHR
Infoway's Interoperable EHR Program is aimed at implementing a lifelong, integrated and patient centred electronic patient record that makes it possible to access information and documentation regardless of time or place. That being the case, a network of interoperable solutions will be developed that will interconnect hospitals, district healthcare centres, other healthcare institutions, pharmacies etc. and improve people's access to healthcare services, quality of care and patient safety; as well as improving the efficiency of medical treatment.

Infostructure
Infoway's Infostructure Programme focuses on the development of a common technical architecture and common standards that ensure the integration and interoperability on clinical IT solutions. The Infostructure programme is composed of four elements:
1. Interoperability Requirements and Architecture
2. Cross-programme Methods and Standards

7 The Electronic Patient Record, House of Commons Health Committee, Embargoed Advance Copy, September 2007
3. EHR Standards Collaboration Process


One result of the infostructure programme is the development of the Electronic Health Record Solution Blueprint (see annex 3), a validated, scalable architecture for interoperable IT systems.

**Standards Collaborative**

Standards facilitate information exchange and create a critical base for interoperability. The Standards Collaborative was formed in 2006 to serve a national coordination function in Canada. The Standards Collaborative is responsible for implementation support, training and maintenance of the EHR standards that are developed within the Infoway framework. The Standards Collaborative is also coordinator of the Canadian SNOMED CT project, the Partnership for Health Information Standards, HL7 Canada, and Canada's collaboration in DICOM (Digital Imaging and Communications in Medicine), as well as – together with the Canadian Standards Association (CSA) – secretariat to the Canadian Advisory Committee to ISO/TC 215.
Discussion

Similarities and differences
Denmark has chosen a solution whereby existing IT systems are retained, and have developed the MedCom standard for message handling between the systems.

England has concentrated on a central solution where the same system is used by everyone. The NHS development, however, demonstrates shortcomings when it comes to user involvement and, above all, the British Medical Association is sceptical about the results.

Canada is focusing on common standards and architectures for interoperability, whilst the development of individual IT systems is done at the local/regional level.

It is difficult to get adequately detailed information. Neither Denmark, England nor Canada appear to currently have a direct equivalent to the NI project. When it comes to processes, one usually works with subprocesses in connection with compiling the technical architecture, but we have not found a comprehensive process description. As far as the technical architecture goes, it seems that both HIAL (Canada, see annex 3) and SPINE (England, see annex 2.1) use HL7 version 3 for message transferring, and even Denmark is discussing a project for mapping MedCom to HL7 v3.

In a document outlining the plans to progress from the new Danish strategy (2008-2012) to precise action plans (Annex 1), there is a planned project that will sketch out an overall picture of the services (and therefore the data access) that could exist in the future. This project could have similarities to the basis of the NI project.

Lessons for Sweden
Influencing factors for success
It is difficult to find clear success factors for national implementations. No one feels that they have genuinely succeeded in fully carrying out their ideas and plans for a national IT implementation within the healthcare sector. The problems appear to be similar in many countries, namely:

- Difficulties in getting a large number of different parties in agreement ('the human factor');

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• Difficulties in defining a common infrastructure for many different purposes (patient care, monitoring, research) – is it actually possible?

• Difficulties getting clinicians to accept (especially doctors who work with healthcare on a daily basis, have a lot of experience in their field and are not already 'technologically corrupted').

Experiences from other countries and descriptions in the literature indicate that there are nevertheless some factors that seem to contribute to a more successful implementation. As such, the following can be discerned:

**Clear responsibility**

In a comparative study that mainly deals with the introduction of electronic patient records in primary healthcare,\(^\text{10}\) it can be seen that an all-embracing organisation that controls and is responsible for the implementation is one of the most important factors for success. At the same time, the recommendation is for a more decentralised approach that assures that the local organisations take their responsibility for the introduction process. A comparison between the Danish and Swedish IT strategies also shows the importance of clear responsibility distribution\(^\text{11}\).

**User involvement**

Various studies\(^\text{12}\) show the benefit of user involvement. In the example with Great Britain, where, with their centralised approach in the NHS, have not progressed nearly as far as planned, insufficient user involvement is regarded as the main reason for the delays\(^\text{13}\).

**Use of standards and standard terminology**

It emerged in the interviews that it was felt that the method of implementation and/or justification of a standard and/or a system was more important for success than which standard and/or system was chosen. The institution of a standardisation body (as introduced in Canada) and a clear timetable for the introduction of such is recommended.

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\(^{10}\) Protti D. 'Comparison of Information Technology in General Practice in 10 Countries.' Healthcare Quarterly 10 (2), 2007, 107-116

\(^{11}\) Axelsson A. 'Think long term and across country borders! – a comparison and assessment of Sweden's and Denmark's national IT strategies.' Bachelor thesis (medical informatics), Institution for Learning, Informatics, Management and Ethics (LIME), Karolinska Institutet, Stockholm 2007.

\(^{12}\) Protti D. 'Comparison of Information Technology in General Practice in 10 Countries.' Healthcare Quarterly 10 (2), 2007, 107-116

Risk analysis and assessment

According to a European assessment\textsuperscript{14} only two countries reported ongoing activities for follow-ups and/or assessments in 2007. Four countries had planned activities. In a recently released pilot study the conclusion is reached that there is a need for a comprehensive view in order to map out the often complex relationships between the various relevant activities, interests and disciplines (such as healthcare, engineering, economy, law etc.). Only when we can grasp the entire concept can we pay attention to the various elements—but even there, the multidisciplinary perspective needs to permeate the development as well as the implementation and evaluation. Comprehensive risk analyses are seen in this context to be a prerequisite for strategic risk minimising and preparation for handling any unwelcome consequences that arise from new solutions\textsuperscript{15}.


The experiences from other countries show that, in addition to clear mandates and decisions, compliance to the standards at the national level and local responsibility when it comes to the actual technical implementation, an initiation process is needed that takes the local circumstances into consideration. It is a time-consuming process that requires a great deal of communication and instruction\textsuperscript{16}. 

As far as Sweden is concerned, the recommendation is to especially look at the countries that have a similar health care system to its own, where healthcare is divided into regions, doctors receive a monthly salary and work at district healthcare centres, and where there are specialised hospitals. Such countries include Canada, Spain, Italy, Holland and New Zealand.

It can also be stated that most countries appear to have the same kind of problems and that Sweden has come a long way when compared with other countries. User involvement is, for example, a point where the Nordic countries are usually ahead of the rest of the world. Even the level of computerisation within healthcare is high and, today, Sweden is in a leading position in Europe when it comes to individual projects like the European summary care record and electronic prescriptions.

It is more difficult to find comprehensive/comparative figures when it comes to computerisation of the healthcare system. Our feeling, though, is that the situation is no better in other countries. However, it seems important for Sweden (and for the NI project) that the national project be clearly coordinated and, consequently, to have distinct mandates and clear responsibility distribution.

Appendix 1, Denmark – From strategy (2008-2012) to action

Digital Health aimed to compile a stable strategy that provides direction during the entire period; that is, until 2012. Digitalisation will make the healthcare system more cohesive between organisations, sectors and municipalities, and across regional and national boundaries. The goal is for doctors and other healthcare workers to have access to the necessary health information regardless of where a person seeks treatment or preventative advice.

Every strategy's design is crucial for the outcome, especially when dealing with such a dynamic area as healthcare, which receives a lot of attention from the general public, the media and politicians. Therefore, Digital Health has chosen to separate the description of the stable strategy from the dynamic action plans. The recently published goals of the strategy are divided into three action plans, and it is during these action plans that the detailed projects aimed at citizens, patients and staff are compared.

The three action plans shall ensure:
1. That staff are given tools that improve quality and productivity;
2. Better services to involve citizens and patients;
3. A common infrastructure.

Guiding principles

It is crucial for success that there is broad support for the strategy and for the action plans that are carried out. Digital Health emphasises openness and transparency, and would like, therefore, to be regularly included in close dialogue with the state, regions, municipalities, suppliers, interest groups, professionals etc. about the digitalisation project.

In the beginning of February 2008, Digital Health holds a workshop that, amongst others, regions and municipalities have been invited to. The purpose with the workshop is to discuss, contribute to and prioritise the potential projects during the strategy's action plans. The result will be the benchmark for an action and project plan, which is available from Digital Health's administration during the first quarter of 2008. The administration decides on the finalisation of these projects, taking into account the utility and costs in relation to the goals of the strategy. The project should, therefore, have unequivocal and communicable value based on the collective needs of the healthcare sector.

Projects approved by the administration that are under way

Before the healthcare digitalisation projects begin, they should always be assessed in consideration of their utility, the current needs of the healthcare
sector, and the potential use that the various parties have for the new digitalisation solutions.

As it stands, the following projects have been started for realising the goals of the strategy:

- Common electronic medicine dossier. The common electronic medicine dossier provides up-to-date information on a patient's current medication to relevant persons in hospitals, practices care homes etc. A doctor who is caring for someone would like to have an overview of the patient's overall medication arrangements – for example medication prescribed by the patient's own doctor but changed after visiting a hospital.

- Upgrading the healthcare system's computer network. Health information should be able to be communicated safely and efficiently. Therefore, the healthcare system's computer network is being upgraded to a high-speed network that can support on-line searches for large amounts of data from all parties within the healthcare sector.

- Web Service test centre. After receiving contributions from Digital Health, MEDCOM has established a Web Service test centre for testing and quality assuring new national Web Services.

- Translation of clinical terminology. In order to assure safe, efficient and automated data exchange, uniform terminology must be used in the IT systems across the entire healthcare sector. This project is based on an international collection of medical terminology called 'SNOMED CT', which is translated into Danish. The project illustrates, amongst other things, the strategy's goal to use to the greatest extent possible the international and national experience that Digital Health has in receiving responsibility for translation from the Danish National Board of Health (Sundhedsstyrelsen).

- Assessment of clinical terminology. An assessment of the translated SNOMED CT has been set in motion in the research-oriented EPR system, which will verify the translation and demonstrate the utility of the clinical terminology.

Projects in the planning/initiation stage

- National patient index. The patient index will provide an overview of healthcare data on the individual patient and supply information from hospitals for the benefit of other hospitals, practising doctors and, of course, the patients themselves.

- National standard for Web Services. It is an objective that all parties within the healthcare sector should have access to information easily and efficiently. Therefore, a national standard for Web Services has been established that is used, for example, for entering data into a central register.

• X-ray service. Exchange of X-ray images and descriptions between various healthcare parties via common services. Investigating the use of HL7 version 3 in a Danish context.

• Common service for the submission of contagious diseases. A common submission service shall be established for making it possible to record all infections into a national register. Initially, a solution will be established for recording contagious diseases.

• Map of medicine proof of concept. Researching the Map Of Medicine (MOM) system used by the NHS could accelerate the development of national clinical guidelines in Denmark. It could also help in deciding if the integration of EPR can be of use as a decision aid in clinical work. MOM currently contains 400 clinical guidelines/patient records that, in such case, would need translating.

• Archetypes proof of concept. Research into how much support the future structuring, development and division of specialised clinical content (SFI – SundhedsFagligt Indhold) can be for IT systems and organisationally.

• National architecture for services. An overall picture is being written up of which services (and therefore what kind of data access) can be established in the long run.

• Role-based user register. Defines and assigns roles to relevant healthcare personnel groups – a part of the basis for assigning access rights and rights management in general; for example, in a national patient index.

• Patient–carer relations service. Contains and provides details on patient–carer relations. The information is used as part of the basis for assigning access rights and rights management in general.

• Assessment of HL7 version 3. Mapping between MedCom messages and HL7 v.3: Analysing the possibilities and any benefits of mapping between two selected MedCom messages and HL7 v.3.
Appendix 2, England – NHS – Electronic Patient Record

Source: [The Electronic Patient Record, House of Commons Health Committee, Embargoed Advance Copy, September 2007].

In 1998, the English government introduced the NHS Information Strategy, Information for Health. The strategy was designed to run until 2005 but was replaced in 2002 by the National Programme for IT (NPfIT), which included the goal of creating an electronic health record that would contain life-long medical information for every NHS patient by the year 2005. It would achieve this goal by linking together local primary healthcare systems. The update also included the goal of establishing an electronic patient record system at every hospital by the year 2005. The NHS Care Record Service (NCRS) is the main aim of the NPfIT strategy and will create two separate EPR (electronic patient records): a national Summary Care Record (SRC) that contains basic information, and a local system called Detailed Care Records (DCRs) that holds more detailed medical information. NCRS will also include a Secondary Uses Service (SUS) that will provide access to aggregated data for maintenance and research etc.

In June 2002, the Department of Health published 'Delivering 21st century IT support for the NHS: national strategic programme', the outline for the national IT strategy (NPfIT). The strategy confirmed the importance of the goals set out in 'Information for Health', but stated that development had been hampered by protected funding, lack of central government, bad value for money and poor network capacity. The strategy would face these problems through a more centralised approach to NHS IT.

The NCRS and the infrastructure required for supporting it are the key points of all NPfIT projects, and receive the largest part of planned expenditure. NCRS will expand and link together all electronic data held about the patient, as well as significantly upgrade hardware, software and the network infrastructure.

The NHS Care Records Service

NCRS will be comprised of a group of systems with distinct roles and purposes as follows:

Personal Demographics Service

The Personal Demographics Service (PDS) is an application supported by the National Data Spine. PDS includes basic demographic information on every NHS patient, including name, address, date of birth, NHS number and current GP.
Summary Care Record

The Summary Care Record (SCR), which is also supported by the National Data Spine, will be a record that holds basic medical data, including allergies, prescriptions, a brief medical history, operations and examinations. An SCR will be created for each NHS patient who chooses to have such a record.

Unlike the DCR, each patient's SCR can be made available to all areas of the NHS for users with the necessary authorisation. The information contained in the SCR comes from existing records from doctors, and – in the future – from other sources where the data is uploaded and saved on The National Data Spine. SCR is one of the main applications running on The National Data Spine and works together with PDS to decide which patients should have an SCR created for them, and to ensure that no duplicate records occur. In order to be able to use SCR, NHS organisations need to be connected to The National Data Spine via N3 (The New National Network for the NHS).

There has been a change in the information that SCR will hold. In the beginning, the idea was that it should contain basic information about known allergies, reactions to medication and other substances, urgent prescriptions in the last six months and repeat prescriptions not older than six months since their date was renewed. As it stands now, however, the information that SCR will store depends on what part of the country the data is entered in – in other words, the information is controlled by local regulations. Since there is uncertainty about what information SCR will contain, it is difficult to foresee what it will be used for. It is intended for SCR to be used as a primary information source for aiding clinicians who do not have access to any records at the first instance, where the patient is not known to the healthcare practitioner, and to help personnel in their work.

The first pilot tests of SCR were originally planned for December 2004, but, because of delays in launching The National Data Spine, the pilot tests were likewise delayed. Consultations about what should be included in SCR also took longer than planned. The pilot tests started in the spring of 2007, about two years later than originally planned.

Patients will have access to their own SCR on the internet through a website called HealthSpace, where they can see and add comments to the record, but not change the information.

One area that was talked about a lot in England is the level to which patients should be able to control what information is included in their SCR and who should have access to it. The Department of Health set out a proposal in June 2007 for a consent system whereby implicit consent only relates to the initial SCR information and includes medication, allergies and reactions. The second stage, to include a patient's significant medical history, is carried out only after discussion between the doctor and patient and requires, therefore, explicit consent. The patient will also have the ability to choose whether or not an SCR should be created at all, and to what degree the clinician will have access to that information.

A planned feature of the consent system is the introduction of 'sealed envelopes', which will allow patients to restrict access to specific pieces of information that they consider particularly sensitive. Such systems are
planned for both the SCR and for DCRs. The Department explained that two different types of 'sealed envelopes' will be available to patients: 'Standard sealed envelopes' and 'Sealed and locked envelopes'. 'Standard sealed envelopes' are visible to clinicians accessing the patient's record but can only be opened with specific authorisation from the patient. 'Sealed and locked envelopes' are not a visible part of the patient's record and its existence is known only to the patient and clinicians with permission to view the information.

Local record systems

Local record systems, the more comprehensive patient records, will continue to be stored in hospitals, GP surgeries and other organisations. Many of these systems will be upgraded as part of NPfIT and paper systems will increasingly be replaced by electronic systems.

The Detailed Care Record

The Detailed Care Record (DCR) will be created by combining information from local systems. As the name implies, the record will hold more detailed information than SCR. The information will be created by linking to or sharing information from the systems used by local healthcare practitioners to produce a detailed electronic record that can be shared across the entire health sector.

'Connecting for Health' has chosen to create DCR by replacing or upgrading large parts of stand-alone IT systems and ensuring that all such systems are interoperable with each other and with the national NPfIT infrastructure. The ultimate aim for the DCR project is to collect information from all such systems and create a shared record. This means that patients can have several DCRs if they have received treatment in different parts of the country.

DCR will probably store details about past and present condition, evaluations, diagnoses, treatments and health plans. The responsibility for implementing the DCR system falls to LSP (Local Service Providers) that work in all five regions in England. They are responsible for upgrading the local IT systems and ensuring interoperability between the systems that are needed for supporting DCR.

A central part of the infrastructure for the DCR system is the New National Network, 'N3'. N3 interconnects all NHS organisations into one private network and will be the hub for all data sharing between separate IT systems. The secure communication system that is required for DCR to be able to share information relies greatly on N3.

Sharing information between organisations and various healthcare institutions requires standardisation and data encryption. Connecting for Health has coordinated the standardisation, which includes working around SNOMED CT for the whole of the NHS as well as the development of an NHS Data Dictionary, so that the meanings of various medical and administrative terms in the context of the NHS have a common understanding. A trial is also under way to expand the use of NHS numbers to serve as unique identifiers for patient data, so as to develop integrated records where it is
possible to link together patient episodes from different hospitals, or different departments within a hospital.

Some elements of the DCR system, such as the N3 network and PACS (Picture Archiving and Communication System), have been delivered on time to hospitals. Other systems, however, such as PAS (Patient Administration System) and ETP (Electronic Transfer of Prescription), have been delayed – which leads to delays in the delivery of a shared record.

**Secondary Uses Service**

The Secondary Uses Service (SUS), which will collect, maintain and analyse electronic health data from various sources, will be included in the new NCRS system. SUS will provide access to aggregated data for the purposes of administration, research etc.
Appendix 2.1 NHS – SPINE

Source: http://www.ringholm.de/docs/00970_en.htm

Summary

SPINE is the English healthcare IT infrastructure aimed at providing patient information from multiple sources to authorised users. SPINE is based on a centralised patient care record, a central directory service and HL7 version 3 messaging.

'The Spine appears to be based on a fairly mature architecture. It has yet to be seen how closely the implementation of the architecture is linked to the centralized organisation of the NHS; this particular architecture may be hard to implement in other European countries. For example, the Dutch national infrastructure [AORTA whitepaper](http://www.ringholm.de/docs/00970_en.htm#ZIM_WP) is based on a "thin Spine" because of privacy laws and decentralized management of healthcare in general.'
Appendix 3, Canada – EHRS Blueprint


The Blueprint was originally developed as a vision for how electronic health record information could be securely and appropriately shared across Canada using information and communications technologies. The Blueprint has evolved since the initial version, providing better definition of how standards-based technology can be used to support data sharing.

The purpose of The Blueprint is to provide the conceptual framework and working principles for the development of electronic health records that can share information across Canada.

The framework's information system structure expresses the current need for being able to share EHR data within the Canadian healthcare system. The building blocks include: individual electronic health records; health information management systems in large and small Point-of-Service applications (PoS); health information storage spaces and data warehouses; and special application services that display and look after the information when it is transferred from one place to another.

The Blueprint is developed around the policy of designing, building and implementing Infostructure, which is needed for the interoperable EHR. This includes the following:

- The framework defines Infostructure as a controlled environment where integrity and security policies, and other clinical data regulations, can be introduced. Infostructure can be implemented at any level of jurisdiction, which will allow good flexibility and configuration possibilities for meeting local and provincial needs.
- Infostructure uses a Service Oriented Architecture (SOA).
- The mechanism for the messaging application meets the pan-Canadian EHR standard for ensuring a clear and uniform understanding of data.
- Design and use of an EHR data domain repository for making it possible to reuse future solutions within a jurisdiction.
- EHR infostructure combines the abilities of a network of interconnected EHR solutions for ensuring access to detailed and complete health records for authorised users in Canada.
- There is no home for a patient's electronic health record. Every EHRi is responsible for setting up and providing access to EHR data for every patient who has received care within the jurisdiction the EHRi works in. If, over time, a patient has received services from
four different jurisdictions, then a virtual EHR exists in each of the four jurisdictions.

- Internal identifiers are required in an EHR infostructure in order to allow all cooperating systems to have easy access to data. These internal identifiers, which provide the correct information to the correct end user, are never revealed to PoS applications.
- EHRS supports both French and English languages.

The method chosen for forming the foundation of the EHRS (electronic health record solution) is to use a shared data reference source that is built on relevant clinical data from various PoS systems. The reference source remains external to the work and does not directly integrate with PoS applications. This method was chosen because it protects both the basic data and the PoS application performance, whilst requiring the least amount of direct interfaces. Another requirement is for standards to be introduced for all data exchanges within the EHRS, which provides more consistent and usable data.

The above figure shows how data can be shared at the same time as fulfilling healthcare requirements and the standards between jurisdictions.

- Every jurisdiction will have its own EHRS that is customised to their needs and nature. Some larger jurisdictions will have a number of EHRS that work together in a region. All will have the same overall architecture that is developed within the framework.
- The information systems that support information maintenance and exchange are distributed across the jurisdiction.
- The features of the clinical information databases are decided by national standards.
- All of the various databases and applications are connected to EHRI (EHR infostructure) so that the information can flow when needed.
An *infostructure* is a shared resource of hardware, software and communications technologies with associated architecture that allows an uninterrupted flow of data. *Infostructure* has a registry system that provides the necessary information for individually identifying different parties and resources in EHR. The identification element includes the name of the patient together with a unique identifier, care giver, point of care, end user for the application and the terminology used for describing illnesses, behaviour or other relevant clinical information. A register that stores patient consent is also part of EHRi. There are also interconnected groups of databases for specific pan-Canadian issues such as public health.

- There is a messaging-oriented model for communication.
- When interoperability reaches the jurisdictional level, by using principles from *The Blueprint*, the potential of being able to access EHR data from anywhere in Canada will become reality.

**Key elements of the EHRS Blueprint**

**PoS applications**

PoS systems are responsible for collecting the clinical data that finally forms a patient's EHR. PoS applications build on the following design principles:

- Maintenance, alteration and design should be done in processes led by clinicians.
- Existing applications that are efficient and adapted for continued use within the architecture contain a lot of knowledge and must be used.
- Every PoS has its data stored locally and communicates with other PoS via the Health Information Access Layer (HIAL), where the information is verified for correct patient identification or anonymisation, depending on what the data will be used for. In addition, a comparison is made with the register to check the point of care, healthcare practitioner and the identity of the person requesting the information.
- Every PoS is an instance of a clinical application so that it can maintain the information without it needing to be shared from the EHR, which is available via *Infostructure*.
- The information sent to EHR for sharing is a duplicate, not the original.

**Shared data: EHR repositories**

In order to be able to handle information that is not stored in PoS applications' databases (e.g. diagnostic services or public health registers), *The Blueprint* includes a small number of EHR domain repositories/interim storage databases that are associated with a province or jurisdiction. Each one will contain a significant portion of the cohesive EHR data that is available for sharing with other domain repositories and jurisdictions.
PoS applications are responsible for supplying data that will be shared to EHR data storage services. PoS applications that work in this way are called 'EHR Source Systems'. The EHR storage then receives that information and stores it in its local database until the data is needed by another authorised user.

All information exchange is carried out through the use of standards based interfaces that are defined in 'EHR Interoperability Profiles'. These profiles define the interface between PoS applications and EHRi. The profile includes descriptions of the types of service requests that can be made to an EHRi, and descriptions of the data that will be exchanged by referring to the data model. The profiles are designed as messages that use defined standards such as DICOM and HL7. The messages are supported by conceptual standards like SNOMED CT and classification systems such as ICD 10- CA. These interfaces transfer data between EHRi and PoS applications.

The complete picture: Longitudinal Record Services
As part of the Services Oriented Architecture that The Blueprint is based on, 'Longitudinal Record Services' carry out the work of gathering and assembling information from registers, storage areas etc. as well as normalising the information for a common understanding. It logs events and takes care of relevant data as an aid to the PoS systems.

Health information access layer (HIAL)
HIAL works as a portal that allows information in different languages and forms to be shared. It provides a standardised method for PoS applications to be interconnected with EHRi, regardless of the way that a jurisdiction has grouped the EHR information domains and services. The idea of having an access point, and the integration of every jurisdiction's EHRi is the principle behind HIAL.

HIAL is composed of services, roles for services, data models and messaging standards that are required for sharing EHR data and performing interoperability profiles between EHR services.

The common window – EHR Viewer
Included along with other PoS applications, but distinguished in that it does not rely on local data storage, but, instead, receives all its information from EHR. This application is designed as a real-time support for every day healthcare for different types of care givers.

Goals
- That there should be capacity for a life-long longitudinal record for a person that can be shared outside an organisation's boundaries and generate the information.
- That every person's information shall be kept and transferred safely and confidentially.
• That there should be a good management and maintenance structure for how a person's health information is handled.
• That information solutions should be sustainable over a long period of time, and that the costs should be in relation to other community priorities.
• That the complex needs should be addressed with a design that is as simple as possible and can be expanded.
• That the information should be available to ensure that the needs of public healthcare are satisfied.

**Approach**

*The Blueprint* project uses the HL7 HDF methodology as a guideline to gather clinical business requirements into a set of use cases at different levels of detail and then realize those use cases into a collection of system design documents. The artefacts used to document the clinical work process are expected to be reusable uniformly within established standards and structured software engineering methodologies, such as HL7, HDF, IHE and others.

In order to provide sufficient details for designing the conceptual and technical architecture based on clinical business processes, use cases are to:

• Record clinical business processes through the use of storyboards and meetings
• Capture the process stream through activity diagrams
• Capture the information structure
• Capture clinical business rules, including relations, events, decisions and restrictions
• Ensure that the HL7 standard is used.