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# 1 Introduction

## 1.1 Background

In November 2012, the Norwegian Government launched [White paper no. 9 \(2012-2013\): \*One patient – One record: Digital services in the healthcare sector\*](#) (In Norwegian). The Government's main objective for the development of ICT in health is that healthcare personnel shall have easy and secure access to relevant health information; the citizen shall have access to simple and secure digital services; and should be made available for quality improvements, health surveillance, governance and research.

In 2013, the Ministry of Health and Care Services commissioned a report from the Directorate of Health, in which different conceptual alternatives for the realization of *One patient – One record* was to be assessed. The report should contain risk assessments and organizational consequences for each conceptual alternative. The work should be conducted in collaboration with the healthcare sector.

The report should cover the following areas:

- Healthcare personnel service provision and patient administration
- Continuity of care
- Process support and decision support
- Health surveillance, governance and research
- The citizen's access to health information and digital services

In parallel with the commission work, the Ministry of Health initiated a revision of the legal framework for eHealth and a [new law for patient records](#) (In Norwegian) was introduced in 2015. The aim of the revision process was to identify and remove existing legal barriers for more patient centric digital information and communication flows.

## 1.2 Aims and Objectives

International mobility, a global health IT market, and cross border R&D collaboration are all factors which increasingly contribute to the internationalization of eHealth.

As part of the *One patient – One record* report, international experiences with eHealth has been explored. Through a series of case studies, we have gathered and analyzed experiences with making national eHealth strategy and the process of realizing these. Through systematic descriptions of these case studies, an analytical space was constructed for reflections about the challenges and possibilities facing Norway within the area of eHealth. The objective has been to broaden the thinking on conceptual alternatives for *One patient – One record*.

Throughout the process of gathering information for this report we have participated in conferences, organized study trips, and engaged in bilateral meetings with representatives from different levels of the eHealth systems in other countries. These encounters have been key to gaining the insight needed in order to write up case studies for the report. They have also served the purpose of allowing us to establish an international network for the exchange of knowledge and experiences on eHealth. This international network has been valuable in the explorative phase of the commission work, and will continue to be so in the following phase, when a conceptual choice is made and should be realized.

The study of international experiences has been organized in two phases.

Phase I:

- Establish an International network for exchange of knowledge and experiences
- Develop a comparative framework to guide gathering of data and analysis
- Develop a long list of relevant case studies and conduct desktop research

Phase II:

- Identify short list of cases for in-depth analysis and organize study trips
- Write up final report with case studies and comparative analysis
- Feed analysis of international experiences into the assessment of conceptual alternatives

### **1.3 Design of study**

#### **1.3.1 Selection of Case Studies**

In the last two decades many, if not most countries have initiated strategic national eHealth programs.<sup>1</sup> In order to limit the scope of this study, we have made a strategic selection of 17 cases based on the following three criteria:

- A need to follow the development in the Nordic countries due to similarities in political tradition, socioeconomic conditions, organization of healthcare, and eHealth history coupled with a strong tradition for collaboration, also within eHealth.<sup>2</sup>
- A need to understand cases that are distinctively different from the Norwegian approach in order to expand conceptual space.
- A need to understand dominant trends in the global health IT landscape.

These selection criteria guided the identification of relevant countries for case studies. A group of researchers from the Norwegian Center for Telemedicine and Coordination assisted in the first search for documentation on these cases.

The case studies are taken from the following countries: Sweden, Denmark, Finland, Estonia, the Netherlands, England, Scotland, Spain, USA, Canada, Australia, New Zealand, and China.

#### **1.3.2 Limitations**

In this study the focus is on national strategies and projects. In particular we have been interested in projects that support the integration of care across levels of the healthcare systems. Our approach has been top-down. This is not necessarily straight forward, as the majority of eHealth activities take

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<sup>1</sup> For example, a key initiative in the European Commission's first Action Plan on eHealth (2004-2012) was to initiate processed for the development of [strategic national eHealth programs](#) in all member countries, an objective that was also fulfilled.

<sup>2</sup> For an example see the report from the Nordic Council of Ministries eHealth group: [http://www.thl.fi/en\\_US/web/en/research/projects/nordic\\_ehealth/nordic\\_council\\_of\\_ministers\\_mandate](http://www.thl.fi/en_US/web/en/research/projects/nordic_ehealth/nordic_council_of_ministers_mandate)

place at the in regions, municipalities and local enterprises, which means that a top down approach to the study of eHealth hides the differences existing within a country. In some cases, we have also chosen to describe regional projects and organizational initiatives, when the scale and scope of these are of such size that they potentially influence the national strategy. Nonetheless, when this is done, it is always with consideration of what is not covered in terms of coordination of care across the healthcare system, and in terms of national responsibilities and functions that the regional/organizational initiatives do not cover.

### 1.3.3 Key Sources

We have conducted two rounds of search for information. The first during Spring 2013, and the second focusing on identifying updates and new releases during Spring 2015. The main source has been resources on the Internet. In particular, we have focused on the web sites of governmental actors and official organizations and sought to identify key documents such as white papers, strategies and action plans, but also project descriptions, status reports, architectural descriptions and news items. All sources are hyperlinked in the text.

The access to Information has varied across the countries. This has to do with differences in documentation practice and transparency regulations in the different countries, in some instances also language barriers. In the cases where we have encountered problems finding written sources, we have organized bilateral meetings and/or phone interviews with representatives from the countries in question.

Given that we have relied mainly on documents from the countries that we study, the sources obviously are subjective by nature. A desktop research as this has been useful for getting an overview of relevant experiences in the different countries. However, it is not sufficient for more in-depth understanding of the functionality of systems, the degree to which strategies have been realized, use of resources, and experiences with implementation. Through the study trips we have aimed to get more in-depth on a limited set of cases to learn about the experiences with realizing policy visions.

For the introductory parts of each case study – demographics facts, political tradition and key figures for healthcare system, we have wanted to strengthen comparability by mainly using information from two sources; [WHO Healthcare In Transition series](#) and [OECD Health at a glance 2013](#).<sup>3</sup> When other sources are used, these are marked as hyperlinks in the document.

In the wake of increasing public investments in eHealth over the last two decades, many countries have produced official evaluation reports and/or national audit office reports to assess the impact of investments in eHealth. For the countries in which this is the case, the findings from the reports are summarized towards the end of each case study as a “final reflection”.

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<sup>3</sup> Please note that updated key figures are available in the 2015 edition of the OECD Health at a Glance series: <http://www.oecd.org/health/health-systems/health-at-a-glance-19991312.htm>

### 1.3.4 Comparative Framework

In order to secure relevance of the report in light of the Norwegian *One patient – One record* program, and enable cross-country comparison we have constructed a comparative framework to structure the descriptions and analysis of the material.

Two objectives have been important in the construction of the comparative framework. First, we have aimed to give the reader an understanding of the socioeconomic and political context for the strategic development of national eHealth projects. Secondly, in order to secure relevance for the Norwegian *One patient – One record* program, the comparative framework is constructed on the basis of the knowledge needs in the work with needs assessment and conceptual assessment. The comparative framework with the list of questions that were used to guide the gathering of information and organize the program for the study trips is attached.

Recognizing that eHealth is a highly dynamic field, with rapid, often disruptive changes of political, technological, professional and organizational character it is challenging to maintain an updated description of different national experiences. Rather than an exhaustive description of national developments, we suggest reading this report as a reference document that provides the reader with an introductory overview of the sociopolitical context, main actors and timeline for the continuous development of national eHealth projects. In order to facilitate further reading into topics of relevance, we have hyperlinked sources throughout the document.

## 2 Sweden

### 2.1 Demographic Data and Political Tradition

Population (2014)	9 592 552
Area (km <sup>2</sup> )	450 295
Political tradition	Unitary parliamentary constitutional monarchy
Administrative levels	State, 21 counties, 290 municipalities

### 2.2 Key Figures for Healthcare System (2011)

Health status	
Life expectancy at birth (years)	81.8
Expenditure on health	
In percent of GDP	9.5
Per capita (USD purchasing power parity)	3 925
Public financing (% of total expenditure)	81.6
Private financing (% of total expenditure)	18.4
Health workforce	
Practicing doctors (per 1000 population)	3.9
Practicing nurses (per 1000 population)	11.1
Healthcare activities	
Doctor consultations (per capital per year)	3
Hospital discharges (per 1000 population)	163
Total hospital beds (per 1000 population)	2.71
Average length of stay, all causes (days)	5.5
Access to healthcare	
Coverage for healthcare (% of total population)	100
Out-of-pocket medical spending (% of household consumption)	3.3

### 2.3 Gathering Information on the Swedish Case

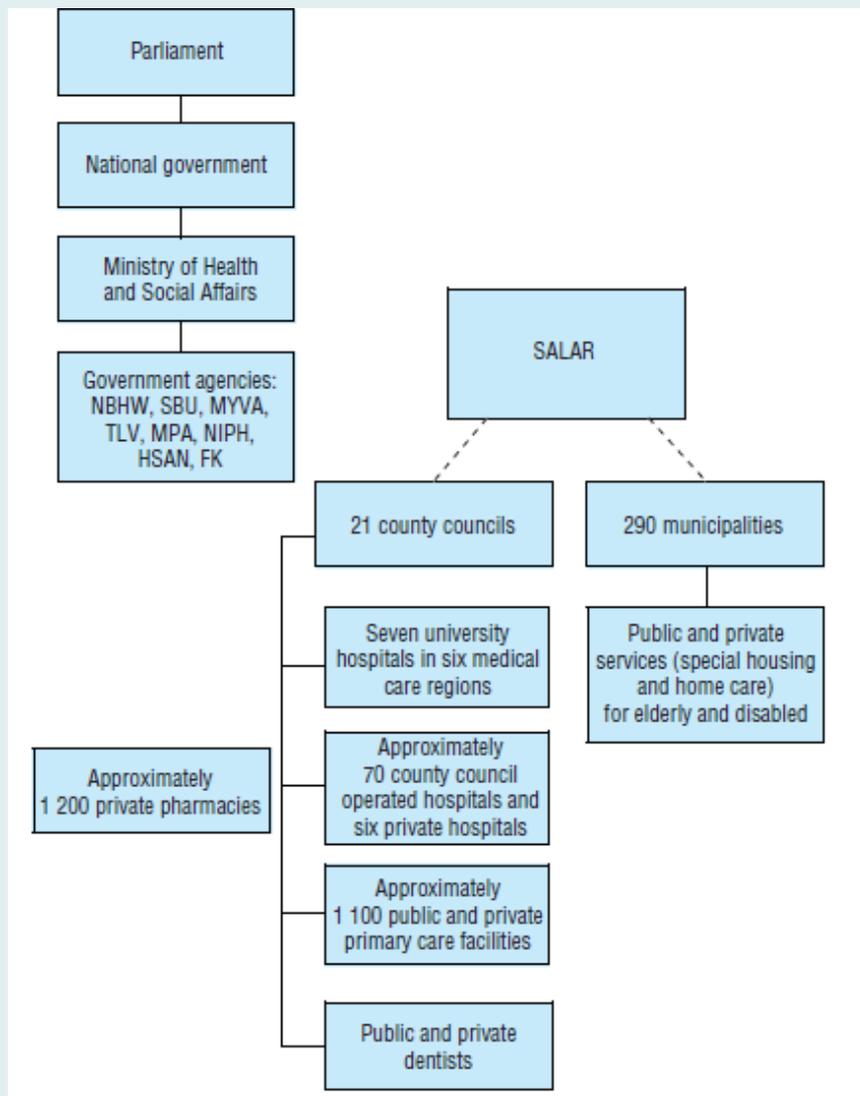
The empirical material for this chapter is gathered in two phases.

Desktop research, May-June 2013: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Swedish healthcare system, eHealth strategy, key actors and initiatives.

Interviews with key actors, February 2015: Henrik Moberg, Deputy Director, Ministry of Health and Patrick Sundström, Head of eHealth Program, Inera AB.

## 2.4 Financing, Governing and Organizing Healthcare

Figure 1. Swedish Healthcare System



Source: WHO HiT Series

Sweden has a universal public health system, largely financed by taxation. About 80 % of all expenditures on health are public expenditures and about 17 % are private expenditures, predominantly user charges.

The healthcare system is organized into three levels: the national (state), regional (counties) and local (municipalities). [The Ministry of Health and Social Affairs](#) has the overall responsibility for policies, legislation, supervision, coordination, and evaluation, and partly finances healthcare

services. There are eight governmental agencies directly involved in the area of healthcare and public health.<sup>4</sup>

Under Swedish law, health service staff must work in accordance with scientific knowledge and accepted standards of practice. [The National Board of Health and Welfare](#) (Socialstyrelsen) is commissioned by the government to provide evidence-based guidelines for the care and treatment of patients with serious chronic illness.

The responsibility for ensuring that Swedish residents have access to good healthcare lies with the 21 county councils and 290 municipalities who have considerable freedom with regard to how they organize services, whether through use of private companies, cooperatives or nonprofit organizations, or by providing services themselves. The proportion of private service providers is growing rapidly.

Both county councils and municipalities are politically elected entities. There is no hierarchical relation between municipalities and county councils since both are self-governing local authorities. Both the county councils and the municipalities levy proportional income taxes on the population to finance service provision. There is no general definition of basic service packages. Service packages and the distribution of responsibilities between municipalities and county councils are the result of political processes internal to municipalities and county councils, and negotiations between them.

Recently, the trend has been more cooperation between county councils and between state and regional and local authorities as represented by [the Swedish Association of Local Authorities and Regions - SALAR](#). SALAR is a collaborative organization that strives to promote and strengthen local self-government and provide local authorities with expert assistance. In addition, it is an employer association.

The county councils are the main responsible for healthcare delivery, including preventive health, primary care and hospitals. Specialised care is offered by the 70 public county hospitals (six private). The counties have formed six regions<sup>5</sup> to facilitate cooperation in tertiary care, each serving a population of about 1 million people. Primary care is provided mainly through 1,200 health centres (40 % private) employing a multidisciplinary workforce. Primary care has no formal gatekeeping function in a majority of the county councils and patients are free to contact specialists directly. District nurses play an important role in primary care, as many first contacts with the healthcare system are their responsibility. District nurses work both within primary care and within the municipal sector. District nurses, employed by the municipals, are involved in home care, and regularly make home visits, especially to older people.

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<sup>4</sup> The National Board of Health and Welfare, the Medical Responsibility Board (HSAN), the Swedish Council on Technology Assessment in Healthcare, the Medical Products Agency (MPA), the Dental and Pharmaceutical Benefits Agency (TLV), the Swedish Agency for Health and Care Services Analysis, the Swedish Social Insurance Agency and the National Institute for Public Health.

<sup>5</sup> The Stockholm Region, the South-Eastern Region, the Southern Region, the Western Region, the Uppsala–Örebro Region and the Northern Region.

The mechanisms for paying providers vary among the county councils. Payments based on global budgets, or a mix of global budgets, case-based and performance-based payment is commonly used in hospitals. Payment to primary care providers is generally based on capitation for registered patients, complemented with fee-for-service and performance-based payments. Physicians, nurses and other categories of staff, both publicly and privately employed, are predominantly salaried employees.

Municipalities are responsible for home care, nursery homes, follow up on chronic care patients, care for the disabled and school health. The responsibility for means testing, and the financing and organization of long-term care services for the elderly and for providing support to disabled people lies with the municipalities. However, the medical responsibility rests with the county councils. The division of responsibilities requires coordination of services for the patient. Coordinated care plans are intended to facilitate more integrated services, not least for the older people. Once a care plan is developed, the municipality takes over the responsibility for the patient.

### ***Healthcare policy reform***

#### **Tensions between local autonomy and regional differences in service delivery on a national level**

Sweden has a strong tradition for local autonomy. Reforms are initiated and implemented by individual county councils and regions rather than at the national level. While the result is heightened sensibility for local variation, less favorable results have been regional differences in quality of care, as well as challenges with regard to coordination of care between counties and municipalities.

During the latter part of the 1990s and the 2000s attempts have been made to strengthen national steering and coordination by commissioning the central agencies to develop national guidelines and action plans focusing in particular on chronic care patients and the coordination of care. Reforms initiated at the national level have focused on the responsibilities of county councils and municipalities, direct benefits for patient groups and regional equality of services. A waiting-time guarantee ([Vårdgaranti](#)) was introduced in 2005 to strengthen the patient's position, improve accessibility and ensure equal access to care.<sup>6</sup>

#### **Specialization and concentration of services within the hospital sector / Regionalization of healthcare services including mergers between county councils**

The Swedish healthcare system is undergoing a shift from hospital inpatient care towards hospital outpatient care and day care, a concentration of highly specialized care and an emphasis on separating emergency care from other forms of care. From an organizational perspective, the focus

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<sup>6</sup> The guarantee is based on the "0-7-90-90" rule – meaning instant contact (zero delay) with the healthcare system for consultation; seeing a GP within 7 days; consulting a specialist within 90 days; and waiting for no more than 90 days after being diagnosed to receive treatment. If the county council is unable to provide elective services within the stipulated targets, patients should be offered care from an alternative provider at no extra cost. In 2008, the guarantee was complemented with a P4P program providing extra government grants to those county councils that complied with targets. The background for this initiative was persistent problems with excessive waiting times, in spite of the care guarantee.

has shifted from reorganization of small hospitals to mergers and collaborations between large university hospitals.<sup>7</sup> The key objective is cost containment through increased collaboration, and quality improvements in service provision and for clinical research. The mergers occur in parallel to regional structural reform - Region Skåne and Västra Götalandsregionen were formed in 1999 by merging two and three county councils respectively. Discussions about the need for similar mergers across additional county councils and formation of additional regions are ongoing.

### **Competition and privatization to support the development of primary care**

Following a wave of New Public Management reforms – local and national - today, patients can register with any public or private provider accredited by a local county council, which means that the primary care providers' responsibility for a geographical population has been formally abandoned.<sup>8</sup> The number of primary care providers has increased by 20 % since the reform, primarily in urban areas.

### **A trend towards more performance oriented governance of healthcare**

Both county councils and the State have increasingly become interested in a knowledge-based form of governance over healthcare services. This interest is in turn based on the emerging overall performance paradigm of governance, giving more attention to the quality and value of healthcare services. Key words are national quality registers, public comparison of quality and efficiency across local authorities and providers, value for money invested in healthcare, health outcomes and benefits from the patient perspective, process orientation, and coordinated service delivery.

A focus on transparency has led to requests for valid performance indicators and improved possibilities for monitoring performance on a regular basis through investments in registers and new IT solutions. In 2006, the National Board of Health and Welfare together with SALAR initiated the project [Öppna jämförelser](#), in which the 21 county councils are compared annually based on a number of indicators that reflect quality and efficiency.

The project has directed focus on information systems. A lack of a national framework for IT applications and solutions in healthcare has also been discussed more generally. As within other areas in healthcare strong local autonomy has led to regional differences in the use of ICT-systems. Different county councils, regions and municipalities have come up with different solutions and are using different information systems that are not always compatible across or even within counties and regions. By law, healthcare employees have access to data from other caregivers in the same county council following consent from individual patients. However, in practice, healthcare personnel often lack the digital solutions to support such information sharing. Consequently, in 2006, the Ministry of Health and Social Affairs, SALAR and several national authorities in the healthcare area introduced a national eHealth strategy introducing a broad set of efforts to improve the situation.

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<sup>7</sup> For example in Stockholm, the Karolinska and Huddinge hospitals were merged into the Karolinska university hospital in 2003, and Malmö university hospital and Lund university hospital were merged into the university hospital of Skåne in 2010.

<sup>8</sup> Registration based on latest visit or shortest geographical distance is practiced in most county councils for individuals who do not make an active choice of provider.

In the following we shall take a closer look at the Swedish eHealth system, starting with an overview of the timeline before describing key components and services.

## ***2.5 Swedish eHealth: Past, Present and Future***

Sweden is among the most mature eHealth countries worldwide, with full to high deployment of EHR systems throughout all sectors, national PACS, and high level of electronic messages. While much effort has been invested in regional consolidation og ICT systems to enable information exchange, electronic coordination remains a key challenge both with regard to the exchange of information between counties, and between public and private providers within a county.

At a national level, the Ministry of Health has the overall responsibility for policy and legal development. Socialstyrelsen is responsible for a coherent national information structure, nomenclature, classifications, quality indicators and documentation procedures. E-hälsomyndigheten is responsible for handling ePrescription, national medicine statistics, and the development of *HälsaFörMig*, a personal online health archive.

The counties, regions, and municipalities are in charge of investment and implementation of ICT in the health sector. They must comply with information handling and reporting requirements set out by SALAR, which also:

- Develops shared specifications for municipalities, county councils and regions
- Negotiate prioritization agreements with the state
- Initiates and contributes to development projects
- Advice, develop guidelines, and create arenas for exchange of experience and development of competence

The county councils and regions have formed a strategic collaboration on eHealth through Inera AB. Inera is both organization responsible for national procurements and provision of national eHealth infrastructure and services.

It is important to note that the members of SALAR can formally decide whether or not to follow the framework developed through SALAR, and whether or not to contribute to and use the solutions developed by Inera.

Sweden has had two national strategies for eHealth. According to the Swedish principal of financing – “Finansieringsprinsippet” – the state shall compensate county councils, regions and municipalities for extra costs that follow measures that involve greater commitment or an increased level of ambition on their behalf. The Ministry of Finance safeguards the principal, and maintains strict control with all new proposals from the other ministries. In practice, the consequence is that a very limited set of state instigated efforts are launched in the area of eHealth. In addition to the national eHealth strategies, SALAR has released a number of action plans since 2005 in which they take the national

strategy as the starting point for detailing shared efforts within the frameworks of the national strategy.<sup>9</sup>

### **Timeline**

**1998:** [Inera AB](#) (In Swedish) established as a SALAR owned, non-profit company that develops and operates eHealth solutions for the county councils.<sup>10</sup> Inera is politically governed, has a program committee and a portfolio office. Inera develops the national health net, Sjunet (In Swedish) in order to ensure safe data exchange between the counties.

**2005:** The National Board of IT in Healthcare (NBITH) is established by the Ministry of Health and Social affairs following an agreement with SALAR, with representatives from Ministry of Health, Socialstyrelsen, SALAR, the Association of Private Care Providers, and Famna - The Swedish Association for Non-Profit Health and Social Service Providers. The agreement formalizes hitherto ad hoc-based collaboration between the state, county councils, municipalities and private providers. The High-Level Group focuses on strategic questions and choices associated with National eHealth, and functions as a body for joint decision-making regarding the focus for future work. The Group has overall responsibility for strategy implementation and for monitoring delivery of various national projects in relation to the action plans drawn up by each actor respectively.

**2006:** NBITH launches [National strategy for eHealth](#) (In Swedish).<sup>11</sup> The strategy should both support local and regional work and lay a foundation for intensified national cooperation, aiming to:

- Improve patient safety, accessibility as well as quality and continuity of care by creating a broad national consensus on future investments in eHealth.
- Enable patient mobility nationally and internationally.
- Meet the increasing demands from citizens and healthcare professionals to integrate healthcare in the information society.
- Encourage healthcare politicians and decision makers to use eHealth as the main tool for renewal and improvement of health services.

The implementation process is divided into six action areas:

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<sup>9</sup> [http://www.inera.se/OM-OSS/styrdokument\\_rapporter/](http://www.inera.se/OM-OSS/styrdokument_rapporter/) (In Swedish)

<sup>10</sup> Before Inera, the company Carelink used to initiate, develop and manage national eHealth solutions in collaboration with its members and other stakeholders. In 2008, Carelink became part of Inera, which continues running the company's projects.

<sup>11</sup> The Swedish national eHealth strategy should be understood in the context of two other cross-sectorial documents, namely the National Action Plan for the Swedish eGovernment (2008) and "An Information Society for all" (2004). The latter is concerned with the Swedish Government's policy to utilize the potential of ICT to stimulate growth, employment, and regional development, as well as to promote societal values such as democracy, equality, fair treatment, and quality of life. In the context of an efficient public administration it also underlines the importance of developing the healthcare system including IT usage. One application area is to further develop national prerequisites for the broad-based implementation of telemedicine. The National Action Plan for the Swedish eGovernment launched in 2008 – even though it is from another domain – deals with eHealth topics. It stresses the importance of creating a common technical infrastructure and facilitating access to information across organizational boundaries of the health and medical care system.

1. Bring laws and regulations into line with extended use of ICT
2. Create a common information structure
3. Create a common technical infrastructure
4. Facilitate interoperable, supportive ICT systems
5. Facilitate access to information across organizational boundaries
6. Make information and services easily accessible to citizens

With financial means from the state and county councils Centre for eHealth in Sweden (CeHis) is established to drive forward joint development, in conjunction with the national strategy. CeHis is responsible for coordinating all national eHealth activities which included the involvement of the county councils in the national work, the follow-up and evaluation of national work concerning interoperability and cost-effectiveness, and reporting to the county councils' CEOs. The assignment includes shared development of infrastructure, regulation and services, as well as procurements and implementation management. The aim is to increase joint efforts among county councils and avoid costly parallel developments. Decisions are made on two levels, centrally by SALAR governing bodies adopting plans, and decentralized by all actors developing a position to proposed plans and taking its share of funding responsibility. Operative responsibility lies with the enterprises. The establishment of CEHIS implied a distribution of responsibilities between CeHis as procurement body and Inera AB as delivery body.

Even though the necessity of a national approach to collaboration and development of core services is stressed in the national strategy, it is clearly stated that the responsibility and the decision are in the hands of the county councils, the regions and the municipalities. The role of the government is primarily advisory. The county councils and regions have since collaborated on eHealth issues through several multi-annual action plans (2007–2009, 2010–2012 and 2013–2018) in which the aim is to coordinate ICT projects more effectively and increase the scope of joint efforts. 21 million Euro per year was set off for the period 2007–2009 for joint development initiatives, primarily focusing on a common infrastructure. For the 2010–2012 period, funding has been raised 31.5 million Euro per year and the focus has shifted to citizen and organizational benefit.

**2008:** The Swedish Patient Data Act is introduced, making it possible for healthcare staff to access, with the patient's consent, patient information held by other healthcare providers by means of direct electronic access.

**2009:** A consultative body – "Samrådsgrupp för Nationell eHälsa", is established to prepare and formalize dialogue among the key actors in the eHealth domain. The advisory group includes government agencies, professional groups, pharmaceutical and ICT industry associations, and national health authorities and care practitioners. The group discusses strategic questions, identifies new focus areas, initiates special working groups and reports to the High-Level Group.

**2010:** An update of the National eHealth Strategy is launched, and the strategy is renamed to [\*National eHealth – the strategy for accessible and secure information in health and social care\*](#). In the new strategy, social services (care) are included and the range of representatives extended to include the Ministry of Social services, SALAR, Socialstyrelsen, enterprises, and Famna. ICT is described as an integral part of healthcare enterprise development. The strategy aims to be patient centric and focuses on process and enterprise development, rather than ICT as such. The main aims are:

**Citizens should have** easy access to quality-assured information about healthcare and social care, as well as access to documentation from previous encounters with the healthcare system. The citizen shall be offered individual service and interactive eServices to promote participation and autonomy according to individual conditions.

**Healthcare and social care staff shall** have access to well-functioning and continuous decision support to ensure high quality and safe care, and simultaneously supporting work processes. Necessary and structured information shall be available as support for decision making on interventions and treatments.

**Decision-makers shall have** tools to continuously monitor the quality and safety, and have access to a relevant and coherent basis for enterprise management, planning and resource distribution. Public and private research shall have easy access to data of high quality, with full respect for the integrity of the individual.

**2012:** CEHIS releases [Action Plan for collaboration between county councils, regions and municipalities in the eHealth area](#) (In Swedish). Municipalities are invited in as owners of the centre. Taking as the starting point the three main objectives formulated in the national eHealth strategy, the action plan details a set of shared goals for counties, regions and municipalities with regard to actual use and experience with shared national services such as citizens portal, eBooking system and enterprise systems. In addition, the action plan emphasizes shared development of regulations, terminology, and technical architecture needed in order to realize the objective of an active citizen role in health and care.

**2014:** CeHis merges with Inera AB. The new name is [Inera – County councils and regions collaboration on eHealth](#). While priorly, CeHis coordinated the procurements of the county councils, SALAR is now given responsibility to coordinate the eHealth development both for the municipalities and the county councils. The ownership and management of Inera remains political, through the county councils, has a program committee and a portfolio office.

[The Swedish eHealth Agency](#)<sup>12</sup> is established and made responsible for handling e-prescriptions, compiling national drug statistics and for the development of HälsaFörMig a personal online health account where citizens can have access and control over the information that the healthcare sector has about them.

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<sup>12</sup> Apotekens Service AB ceases to exist, and parts of its responsibilities are transferred to the eHealth agency.

### **Challenges and future developments for the Swedish eHealth system**

Today, Inera coordinates the county councils and regions shared eHealth efforts, and develops, delivers, manages and operates national infrastructure and services. National coordination occurs through NBITH, which has the overall responsibility for follow-up on the national eHealth strategy. The board focuses on strategic questions and directions for eHealth and functions as the arena for shared decision making when it comes to future priorities. The board also oversees that the action plans developed by each actor is in accordance with the national eHealth strategy. The advisory board is responsible for preparing and formalizing dialogue with all key actors in the sector. The advisory board discusses strategic questions, identifies new focus areas, initiate work groups, and reports to the NBITH.

The Swedish governance and financing model is currently being evaluated. The reason is twofold.

First, it has to do with increasing demands for (electronic) coordination and the need for stronger national steering and coordination. One of the main problems today is not a lack of collected data but the fact that the information for the most is unstructured and thus not accessible or usable presented in different ways for different target groups. Secondly, it has to do with a difficult economic situation in the county councils and municipalities. About 3 % of the county councils and regions total investments in ICT is used on eHealth. Costs have remained at the same level the last four years, despite increasing level of ambition and a significant increase in use of infrastructure and services. In the enterprise plan for 2015, Inera stresses that future developments demands substantial investments for the upcoming years. It is further pointed out that the financial leeway in the county councils and regions shared budgets for development projects is decreasing because of increasing management and operational costs.

As a response to among others these challenges, three parallel alternatives have been proposed, each could potentially alter the direction of the Swedish eHealth system.

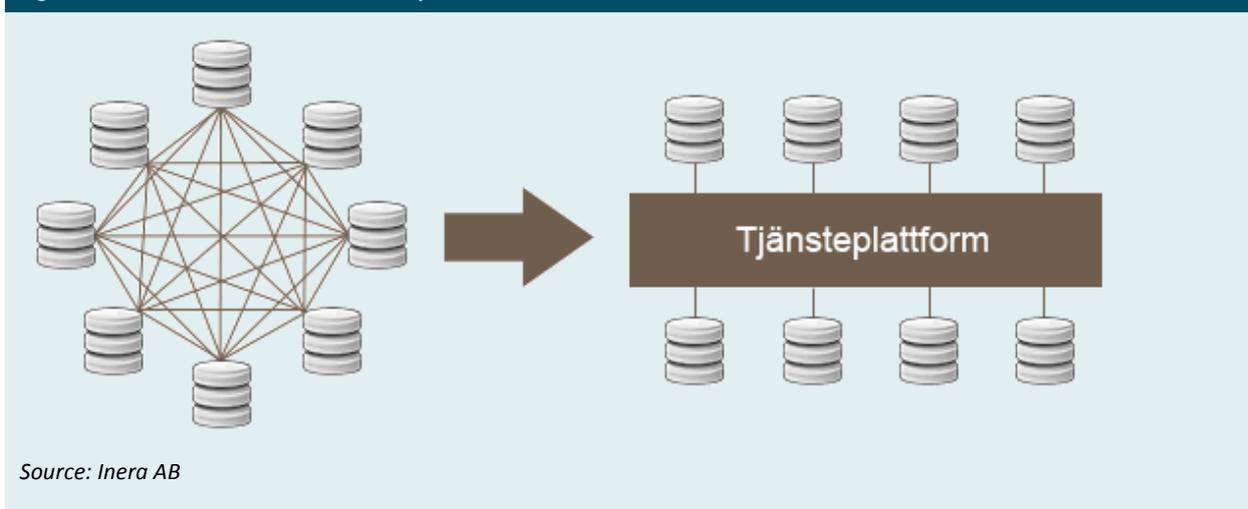
1. At the collaborative regional level, plans are made for SALAR to take over the ownership of Inera from the county councils, and by that the responsibility for architectural governance. The aim is to strengthen coordination between county councils, regions and municipalities in the area of eHealth. SALAR is in the process of developing a suggestion for principals and guidelines for steering, financing, embedding and criteria for prioritization of shared digital solutions for municipalities, county councils and regions. The current action plan calls for the actors to invest more in eHealth, to see their investments in eHealth in relation to other IT investments, and to rationalize maintenance organization. A financing model is proposed that seeks to avoid parallel development and management of tasks and solutions that could be done by one actor on behalf of the rest.
2. Another regional collaborative program – 3R ([website in Swedish](#)), was formed in 2014 as Skåne region, Stockholm county and region Västra Götaland launched plans for specifying, procuring and implementing a shared IT platform within 2020. The program is significant both in scale and scope, involving the entire range of healthcare services for 5 million citizens. The goal is to develop an information milieu which creates the condition for process and decision support systems, communication across healthcare system and citizens, and a tool for steering, management and administration. The aim of the program is to contribute to and support national initiatives and develop a more robust infrastructure for information sharing, ultimately procuring a coherent system with the potential of reaching national scale.

3. A report commissioned by the government in 2013 was delivered in 2015 recommending a new governance and financing model based on strengthened national steering and control with eHealth development; [SOU 2015:32 Nästa fas i e-älsarbetete](#). The committee stresses that SALAR lacks formal steering in relations to its members, and therefore that problems concerning coordination of care will be solved by establishing shared ownership to Inera under the SALAR umbrella. The committee argues for stronger national steering, in particular when it comes to storage of critical information and standards for semantic and technical interoperability. To this end, it recommends to establish a national high level board for strategic decision making on eHealth, under the leadership of the Ministry of Health and with delegated responsibility to the eHealth Agency (technical infrastructure and services) and Socialstyrelsen (standards for semantic interoperability). Furthermore, a national tribunal - a "Samverkansnämnd" - should be established, with legally mandated decision making power in the eHealth domain. As a first priority, the report recommends starting with the area of medication information. A financing model based on co-funding is suggested to support national initiatives.

## 2.6 Current National eHealth System

### 2.6.1 Infrastructure

Figure 2. Illustration of national Service platform



Inera AB operates the infrastructure for the enterprises within healthcare. [Sjunet](#) (In Swedish) is a national quality-assured network for all electronic communication in the healthcare services. Sjunet is used by regional and national services such as ePrescription, transfers of EHRs and x-ray images. Inera decides on the rules for which actors can connect to the network (how to connect, capacity etc.). All county councils, regions and 93 municipalities, 197 private service providers, 30 pharmacies, state agencies and 89 service vendors are connected.

**The national integration architecture and a national service platform** enable secure and efficient integration between different ICT systems in the healthcare system. Every service that connects to the service platform has to sign a service contract specifying the rules for how information exchange should occur between the ICT systems. The solution builds on the following components:

- Standardised transfer protocol (RIV TA)

- Standardised format for messages (Tjänstekontrakt)
- Crossroad choices are made at a central access point (Tjänsteplattform) by means of logical addresses
- A service directory catalogue is used to collect directory information and information about professionals.

The work on the infrastructure is regarded as a key component for the coordination of eHealth cross the sector. Main activities for this are the development of a **shared service platform** and service contracts which are included. The development takes place according to Ineras architecture and includes technical and informatics standardization. A dedicated team of experts - [Integration Competence Center \(ICC\)](#) (In Swedish) - handles integration with the service platform. The centre shall strengthen the overall responsibility for all of Ineras integration solutions, offer support to integration work, support roll out of new services and handle and support administration of service domains.

### 2.6.2 Infostructure

By developing the Swedish National Information Structure and the National Interdisciplinary Terminology, the National Board of Health and Welfare seeks to lay the foundation for more structured, unambiguous and user-friendly documentation in both healthcare and social services.

**The National Information Structure (NI)** is a generic description of the core process in health and social care and the type of information needed by different stakeholders. NI also describes how this information should be structured so that it can be used in different contexts in different parts of the process. The purpose is to enable relevant information to “follow” the patient over time and over organizational borders irrespective of where (by which healthcare provider) the information has been documented.

**National Interdisciplinary Terminology for health and social care (NF)** includes nationally agreed concepts and terms as well as national and international classifications. It also includes the international reference terminology SNOMED Clinical Terms.<sup>13</sup> By the summer of 2010 SNOMED CT had been fully translated into Swedish. However effects with regards to widespread use of the standard remains to be established.

### 2.6.3 Privacy, Information Security, Access Control

[Basic services for information management](#) (In Swedish) is responsible for supplying the role and authorization management services for secure information handling across organizational boundaries required under Sweden’s Patient Data Act. BIF requires the use of Sjunet, the Health Service Address Registry (HSA) and Secure IT in the Healthcare Sector (SITHS) and contains supplementary functions for validation, consent, access control, traceability, logging and log analysis.

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<sup>13</sup> See the report from Socialstyrelsen [SNOMED CT should Sweden join now or wait?](#) Which formed the basis for the government decision to join SNOMED Standards Development Organization (SSDO).

[Health Service Address Registry](#) (In Swedish) supplies information on the working tasks and roles of healthcare staff. It forms the basis for authorizing individuals to register and read confidential information. HSA contains about 320 000 items, i.e. individual staff members and care units. HSA also constitutes the basis for several different healthcare search services.

[Secure IT in the Healthcare Sector \(SIHTS\)](#) (In Swedish) is a national security solution for electronic identification and the secure communication of information. Using the SITHS card, caregivers can identify themselves and verify their authorization, independent of organizational and geographical boundaries.

#### 2.6.4 Shared Components and Services

The Swedish eHealth Agency is responsible for [ePrescription](#) (In Swedish) services, which includes registries, decision support systems, and cross border ePrescription service between Sweden and Finland.

Inera AB has developed a range of eHealth [infrastructure solution and services](#) (In Swedish).

[The National Patient Summary \(NPÖ\)](#) (In Swedish) is a central part of the National eHealth Strategy. NPÖ is a centralized service containing patient information and links to information stored locally in other health institutions. Each and one enterprise decides which information should be available and publishes this in NPÖ. The aim is to improve patient safety and continuity of care. Using the system, all authorized care staff have access to an individual's health records in other counties, municipalities and private healthcare organizations, provided the individual has given consent. The patient can give consent to individual healthcare personnel or institution, for 24 hours or another specified time interval, conditioned that the patient is in a treatment relationship with personnel or institution. Solution includes emergency access option for life threatening situations. The solution differentiates between users as «producers» (can read and edit information) and «consumers» (read only – typically municipal home based care services). What information actually is available in NPÖ varies among the counties and the municipalities. NPÖ is structured according to three levels:

- 1) Patient information and symbol signaling whether there is information about the patient in other systems.
- 2) Timeline showing contacts with the healthcare system, three years back and one year ahead.
- 3) Overview of the five last documents in different categories.

[Pascal \(Comprehensive information on patients' drug prescriptions\)](#) (In Swedish) is an ordination tool for multi-dosage ordination which is now implemented in all county councils. The aim is to give every drug prescriber access to a patient's total medical medication history, regardless of where and by whom the drugs were prescribed. An integrated prescription list of this nature gives the prescriber a comprehensive picture of the patient's entire medical drug history. This aim is achieved by using existing information in the Swedish Prescribed Drug Register, the National Prescription Database and the National Dose Register and, based on this information, creating an integrated prescription list.

[Nationell ordinationsdatabas, NOD](#) (In Swedish) is the project making a shared list of medication to be implemented within the framework of a EHR system, as well as technical services to be able to write and read in the list. County councils and regions have committed to financing integration with their EHR systems and NOD. Inera and SALAR have made a report to the ministry regarding

requested changes in the "receptregister" law. Without amendments it is not possible to realize the solution.

### 2.6.5 EHR Landscape

Several different IT systems operate in the Swedish healthcare sector. Generally, both the quality of such systems and their levels of use in hospitals and primary healthcare facilities are high.

Five vendors dominate the Swedish EHR market for county council and regions with 96 % market share (Siemens, Evry, Cambio, Compugroup and the county of Norrbotn), the majority of which have foreign ownership.

**Shared care modules** are part of all the EHR systems in use in the county councils. Solution makes it possible to develop individual patient plans in coordination with the municipalities (most normal are Medixx and Prator).

**Decision support systems** are not commonly used. Systems for handling medication are the exception, a domain in which structured data and national control with ePrescription system.

Intensive work is ongoing to consolidate ICT systems in the county councils, both with regard to own system portfolio and connection to national solutions. The vision is one patient – one record, with a shared medication list and shared terminology and structure.

### 2.6.6 Digital Services for Citizens

[1117.se](http://1117.se) (In Swedish) is an online citizen portal for developed by Inera which gives access to quality assured information about health topics. 1117.se The range of eServices that has been developed for citizens are accessible through log in at 1117.se The service providers decide for themselves what and when they want to adopt these services in their portfolio.

- The 2008 Patient Data Law gave Swedish citizens the right for digital access to their EHR. In 2014, 50 % of the county councils had introduced [Journalen](#) (In Swedish) - a service that allows the citizen to access their health information online. The service is provided through two projects, one run by Inera, and the other by Stockholm län. Both services are accessible for the citizen through 1117.se
- [My Healthcare Contacts](#) (In Swedish) gives citizens the possibility to, for example, change their doctor's appointment online, renew a prescription, ask questions and obtain advice. An increasing number of more advanced services are gradually being developed and made available in step with the modernization of the technical platform.
- [UMO](#) (In Swedish) is a national online youth clinic aimed at young people between 13 and 25 years old. The site is run by Inera AB (previously the national healthcare helpline Sjukvårdsrådgivning SVR AB) in close collaboration with Sweden's youth clinics, county councils, municipalities and youth-oriented organizations. The aim of the site is to make it easier for young people to find information about sex, relationships and health. UMO currently has around 170 000 visitors a month. Offers digital consultation with healthcare personnel.
- [Online support and treatment](#) (In Swedish) is a national service that provides patients with specific treatment programs for instance on anxiety and stress relief, follow up in between

intensive treatments such as heart surgery, interactive dialogue with healthcare personnel, possibility for registering their own data in between consultations.

The Swedish eHealth Agency is currently developing [HälsaFörMig](#) (In Swedish), a personal online health account where citizens can have access and control over the information that the healthcare sector has about them. The plan is to release the service in 2016.

### 2.6.7 Secondary Use of Data

There are about 90 national quality registers in Sweden that represent a comprehensive data source for comparative studies and play an important role in work related to monitoring and evaluation of healthcare quality. There are four competence centers for the national quality registries with central funding. The vision for the quality registries and the competence centers is to constitute an overall knowledge system that is actively used on all levels for continuous learning, quality improvement and management of all healthcare services.

Socialstyrelsen develops norms and standards, provides support and supervises that these are observed through data collection and analysis, and disseminates information. The Board also maintains health data registers and official statistics.

The Swedish Agency for Health and Care Services Analysis is responsible for analyzing and evaluating implemented measures, and the availability of information within the sphere of health and care service policy from the perspective of citizens and patients.

Data from the quality registries is published by Inera as [quality indicators and performance data](#) (In Swedish) which enable comparison between county councils, regions and municipalities.

Statistics both on enterprises and patients is made available through [Ineras statistical service](#) (In Swedish), which also provides data from the Swedish [biobank data](#) registry (In Swedish).

Inera also offers a process service for reporting, analyzing, and handling unwanted incidents (In Swedish).

## 2.7 Final Reflections

In the last two decades, the Swedish healthcare system has undergone major structural reforms which have resulted in there being a larger number of healthcare providers now than was the case a few years ago. The national healthcare guarantee for free choice of healthcare provider means that more providers are involved in caring for patients. As a consequence it has become increasingly important to guarantee an efficient, safe sharing of information between different healthcare providers.

In 2011, the Swedish National Audit Office conducted an audit to determine whether Government initiatives have contributed to the objective that authorized healthcare staff shall have access to the right patient information at the right time by means of direct electronic access.

The report [Correct information at the right time in healthcare and nursing – collaboration without effect?](#) points out that healthcare staff has very limited access to electronic patient information held by other healthcare providers, despite this being a main objectives since the release of the first

national eHealth strategy in 2006. The audit report focuses on Government initiatives and their contribution to achieving the objective.

- The Government has created preconditions that enable healthcare staff to have direct electronic access to patient information held by other healthcare providers, but there has been insufficient guidance on interpreting and applying the legislation.
- Socialstyrelsen supervises on the basis of patient safety, while the Swedish Data Inspection Board bases its supervision on personal integrity. There is a risk that these supervisory roles will overlap.
- The involvement of municipalities in efforts to facilitate the sharing of information has been limited, despite an emphasis on their involvement at an early stage of the work.
- The Swedish Patient Data Act does not regulate, and thus does not enable the inclusion of those not competent to make decisions in a shared EHR system. These individuals will often require help from various providers in the healthcare sector and are thus to a large extent dependent on healthcare staff having access to all relevant patient information.
- Socialstyrelsen has developed an information structure and a national specialist terminology for healthcare. However, there is no clear allocation of responsibility for the administration of the national information structure. This can lead to the occurrence of local versions of the national information structure, which risks compromising the concept of creating national standards.
- The form of collaboration chosen between Government and municipal bodies lead to difficulties in driving work forwards towards shared objectives. In the joint national strategy one of the objectives is information sharing across the healthcare system. Yet no single body has overall responsibility for the result of this joint work. This has led to a lack of clarity and problems with coordination.
- The joint strategy has focuses on facilitating the sharing of information at national level, despite the fact that most bodies expressed the view that the sharing of information within the county council should be prioritized.

While the challenges pointed out by the Audit report are well-known, there are conflicting views on how to meet these challenges in the future development of the Swedish eHealth system. The 2013 report from the Government appointed commission *Nästa fase i eHälsoarbetet* recommended more national control through the establishment of a national tribunal for eHealth, the municipalities, county councils and regions through their strategic collaboration within SALAR recommends that future development is organized and controlled at a regional level. However, even among the regional level actors there is no agreement that this is the best way forward, as illustrated by the 3R program.

To conclude, while Sweden has a highly mature eHealth system, with a range of shared infrastructure components and services, there are uncertainties regarding the further development towards a more tightly integrated national eHealth system. The question largely concerns the development of a national model for steering, governing and financing of eHealth.

## 3 Denmark

### 3.1 Demographic Data and Political Tradition

Population (2013)	5 613 706
Area (km <sup>2</sup> )	42 916
Political tradition	Unitary parliamentary constitutional monarchy
Administrative levels	State, region, municipality

### 3.2 Key Figures for Healthcare System (2011)

Health status	
Life expectancy at birth (years)	79.8
Expenditure on health	
In percent of GDP	10.9
Per capita (USD purchasing power parity)	4 448
Public financing (% of total expenditure)	84.7
Private financing (% of total expenditure)	15.3
Health workforce	
Practicing doctors (per 1000 population)	3.5
Practicing nurses (per 1000 population)	15.4
Healthcare activities	
Doctor consultations (per capital per year)	4.7
Hospital discharges (per 1000 population)	172
Total hospital beds (per 1000 population)	3.13
Average length of stay, all causes (days)	4.5
Access to healthcare	
Coverage for healthcare (% of total population)	100
Out-of-pocket medical spending (% of household consumption)	2.5

### 3.3 Gathering Information on the Danish Case

The empirical material for this chapter is gathered through:

Desktop research, May-June 2013 and January-March 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Danish healthcare system, eHealth strategy, key actors and initiatives.

Study trip: A study trip was organized in May 2015 around the following program:

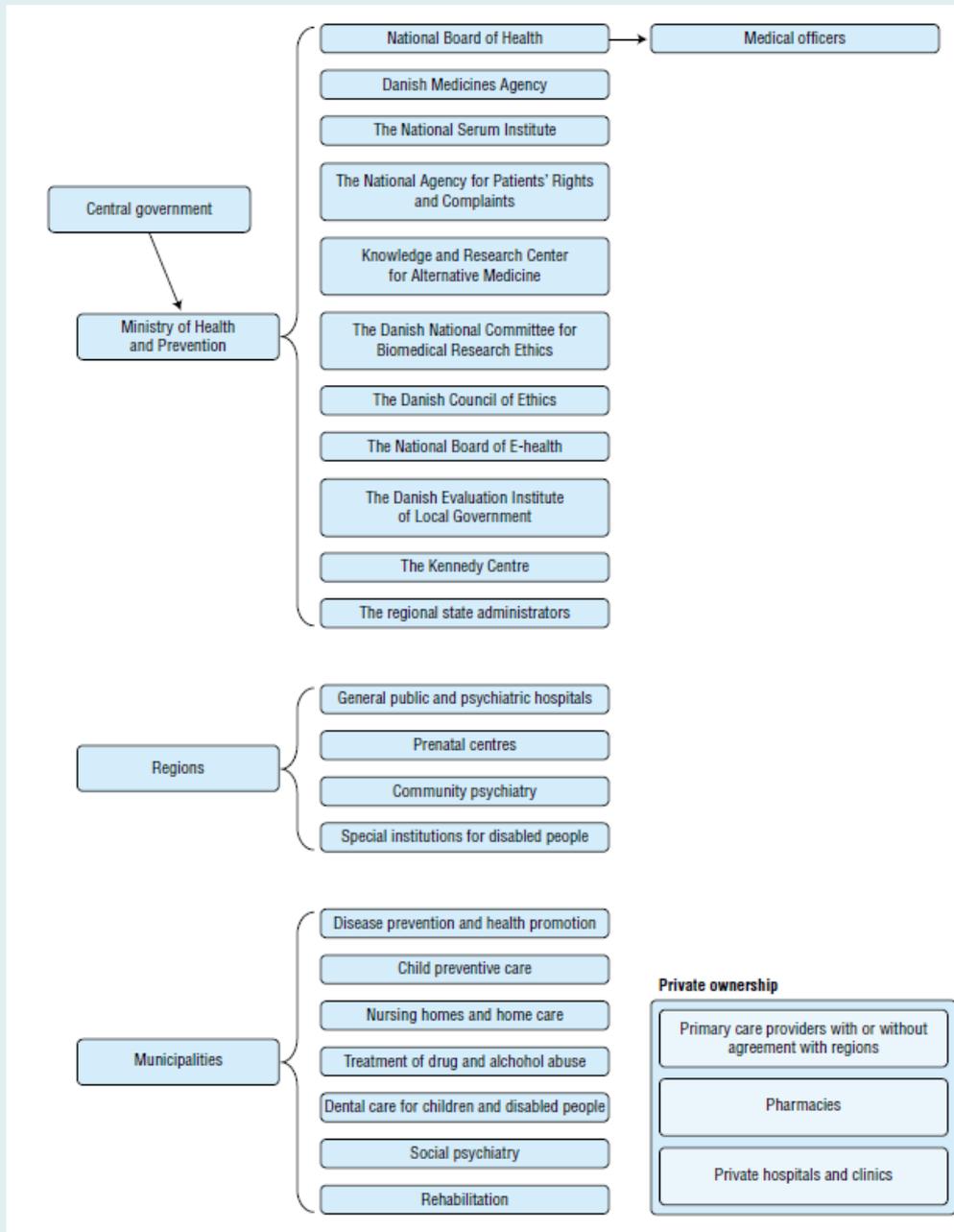
TENTATIVT PROGRAM NORSK STUDIETUR TIL DANMARK VÅREN 2015		
REGIONAL OG KOMMUNAL INVESTERING I OG IMPLEMENTERING AV E-HELSE		
Onsdag 27/5	12:00	Regionernes Sundheds-It (RSI)
	15:00	Kommunernes Landsforbund, KombIT
NASJONAL STYRING OG FINANSIERING AV E-HELSE		
Torsdag 28/5	09:00	Sundhedsministeriet og Nasjonal Sundheds-It (NSI)
	11:00	Digitaliseringsstyrelsen
	13:30	Financeministeriet
REGION HOVEDTADEN OG REGION SJÆLLAND FELLES ANSKAFFELSE AV IT PLATTFORM		
Fredag 29/5	09:00	Region Hovedstaden

On the basis of the information gathered throughout the study trip, the report has been revised and updated focusing on the Danish experience with realizing policies in practice.

In this chapter on Danish eHealth we will use the empirical material to describe the past, present and future of the Danish eHealth system. Obviously, the description is not exhaustive. The content of this report reflects the knowledge needs of the Norwegian *One patient – One record* program. When situated perspectives and viewpoints are expressed, we highlight this by referring to the source. To validate the findings, the Danish host institutions will be invited to add their comments and corrections to the report.

### 3.4 Financing, Governing and Organizing Healthcare

Figure 3. The Danish Healthcare System



Source: WHO HiT Series

Danish citizens are entitled to free and equal access to public healthcare services with universal coverage. Traditionally, the Danish healthcare system has been characterized by a high degree of local autonomy in the shaping of specific solutions and benefit realization. Following more than a

decade of structural reforms, major changes have been implemented to introduce more central control of planning and coordination. Starting with patients' free choice of hospital (1993) and the introduction of a waiting time guarantee (1997)<sup>14</sup>, extending patient's free choice of provider to include private and foreign hospitals (2002), and, finally culminating in the Municipal reform of 2007, in which 13 counties were reorganized into five regions, and 272 municipalities reduced to 98. The aim of the structural reform was to ensure equal standards of care throughout the country by assigning state bodies with more power in planning and quality management. A main driver was the perception that larger catchments areas were needed to support future specialization and to secure structural adjustments in the face of increasing expectations for the quality of healthcare.<sup>15</sup> The Municipal reform would reduce pressure and allow for specialization in the hospital sector by giving the municipalities more responsibility for healthcare, while simultaneously giving them greater financial and professional sustainability.<sup>16</sup>

Another driver for the reform was the pursuit for equitable healthcare. Up until the 2007 reform, Danish politicians had prioritized local autonomy and its potential for innovation over geographical equity. This led to geographical differences with regard to waiting times, availability of medical technologies, and rates of specific diagnostic and curative activities.<sup>17</sup>

The 2007 reform introduced a new financing scheme based on municipal co-financing. Today, healthcare is largely financed through a national earmarked health tax (8 % of income) and redistributed in terms of block grants to regions and municipalities. 80 % of all regional healthcare activities are financed through these block grants in addition to some activity-based (DRG) payments (5 %).<sup>18</sup> The remaining funding comes from a combination of per capita and activity-based payment contributions by municipalities. With the structural reform, co-financing was introduced as an incentive for municipalities to invest in health prevention and health promotion.

Analogue to the political system, today the Danish healthcare system is organized around three levels, the central government, five regions and 98 municipalities:

Central authorities coordinate and give general direction for healthcare policy through [the Danish Ministry of Health](#) (Sundhedsministeriet). The ministry develops broad guidelines for general planning in the healthcare sector and operations in the healthcare services. The Government has a strong focus on quality. In 2004, the quality program *The Danish Quality Model* was established. The

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<sup>14</sup> Reduced from three to two months in 2002, and then finally to one month in 2007.

<sup>15</sup> The idea is that 200.000-400.000 persons is needed to secure quality and allow for sensible staffing.

<sup>16</sup> The rationale has been challenged by several studies, see for example Christensen et.al 2005; Søgård 2004. The political decision making process behind the reform, which was passed with a minor majority, also represented a break with Danish tradition of demanding a strong consensus for issuing structural change.

<sup>17</sup> <http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/eurohealth/VOL12NO4/7Strandberg-Larsen.pdf>

<sup>18</sup> The size of these block grants is calculated using a formula where expected needs for healthcare in the population are a central component. The level of needs is assessed by combining the distribution of age and socioeconomic status in the region. The purpose of activity-based payment is to encourage the regions to increase activity levels within hospitals.

program focused on accreditation standards and the development and monitoring of indicators for healthcare and is run by [the Danish Institute for Quality and Accreditation in Healthcare \(IKAS\)](#).

Municipalities are responsible for social services, rehabilitation, practicing specialists, dental care, and home based care, preventive work public health, and care for children. The municipalities are also responsible for following up on chronic care patients, which has led to ongoing efforts with development and deployment of telemedicine in the municipal sector.

The five regions are the main providers of healthcare services. Following the 2007 reform, regions are responsible for most treatment-related health tasks, including the hospitals, partly or fully financing private practitioners such as GPs, and specialists. Private practitioners are self-employed, but reimbursed for their services by the regions based on transfers from the state and the municipalities. GPs act as gatekeepers to the hospital sector. As a consequence of the waiting time guarantee and the increase of private insurance, the number of private (non-profit) hospitals and the use of contracted private providers has increased.

The establishment of larger administrative units in the 2007 reform paved the way for a DKK 25 billion investment fund for the modernization of the hospital sector (2010). The first major planning task for the new regions was to redesign the hospital sector based on guidelines from the National Board of Health. Quality was to be prioritized over geographical immediacy. The hospital plan has led to a consolidation of hospitals, strong focus on adherence to centrally issued guidelines<sup>19</sup>, control with distribution of specialists, and a pre-hospital acute service plan to compensate for fewer hospitals with 24/7 emergency departments. The latter involves restructuring hospital acute care by centralizing the 24/7 function in 40 hospitals into 21 shared “joint acute wards”<sup>20</sup> and four trauma centers are established across the country. Changes are to be completed by 2020.

The acute wards will be established according to regional plans for aims, principals and operative framework. In the joint acute wards, emergency and acute patient admissions are organized in *one* ward. This is a change from the more specialty-oriented to a more process-oriented admission, transcending professional as well as specialty barriers. The aim is to optimize clinical pathways, starting from acute admission. The expected result is reduced waiting times and fewer unnecessary admissions. Digital solutions are developed to support the joint acute admissions, promoting rapid diagnostic evaluation, standardized workflows and patient pathways as well as improved resource and capacity utilization. Before the end of 2015, the regions will procure and implement shared pre-hospital health records.<sup>21</sup> In addition, the use of electronic boards that provide an overview of

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<sup>19</sup> Clinical pathway for cancer developed and implemented from 2000 - 2011

<sup>20</sup> “Shared acute wards» denotes the physical location in a hospital where acute ill or injured patients can be assessed or hospitalized, and where it is possibilities for diagnostics and treatments with acute clinical intervention from several specialties; staffing includes doctors, nurses and other personnel.

<sup>21</sup> The purpose of introducing the pre-hospital health record will be to improve the treatment for the individual patient, from when the emergency operations center receives an assignment until the patient has been signed over to the joint acute admission at a hospital, for instance through sharing patient data between the unit transporting the patient and the hospital receiving the patient.

capacity and resources is implemented to support production planning and logistics functions at joint acute admissions.

In the recent years, following the re-distribution of responsibilities and increasing inter-dependency created by specialization, the need for a more coordinated healthcare system has attracted considerable attention. In order to ensure coordination, regions and municipalities enter into binding partnerships within health coordination committees. In addition, the state is increasingly taking responsibility for more specific planning activities such as quality monitoring and planning of the distribution of specialists at the hospital level. The annual national budget negotiation is the key arena for planning activities and increasingly used by the central government as a means for reaching agreement on the development of the health sector and for setting the overall economic framework - also for eHealth ("Digitaliseringsbilag"). The negotiations results in agreements on resources allocations, such as level of taxes, state subsidies, redistribution or financial equalization, and earmarked grants.

The current aim for health policy is that citizens shall meet a modern and efficient healthcare system of high quality. Treatment should be organized according to the patients possibilities, time and needs, and with the patient as an active partner. The healthcare system should take as its starting point the tasks at hand, not the current structure. While tasks remain, the way work is organized may change. Consequently, digital solutions shall support patient trajectories rather than enterprise needs:

- Digital solutions shall support **an active patient/citizen role** by enabling access to own health information and information about the healthcare system, and communication with other patients and professionals.
- Focus on **quality, research and learning** based on evidence based practice will give rise to better services that connect across disciplines and system.
- Continuity of care through **good and safe communication** which supports collaboration across.
- Focus on **prevention rather than treatment**.
- With efficient work tools, such as decision and process support tools, time is made available for patient treatment and disciplinary development, making **the healthcare system an attractive employer**.
- **Efficient use of resources** by optimizing day to day operations with the use of relevant clinical and/or administrative data.

In the following, we shall take a closer look at the Danish eHealth system. We start with an overview of the timeline, before looking at the key components and services which make up the current Danish eHealth system.

### ***3.5 Danish eHealth: Past, Present and Future***

When the Danish health authorities established a National Patient Registry in 1977 – a system that required doctors to file visitation notes to the government health service in order to be reimbursed for their work – the country unknowingly laid the groundwork for electronic health records by putting in place a centralized record keeping.

Integrated information systems and electronic health records have been major priorities in the health IT strategies since the late 1990s. In 2010, 90 % of all clinical communication between primary and secondary care was exchanged electronically.

The Danish population has high expectations for healthcare delivery, and for the use of ICT in health. Denmark has set out to take the role as an international innovator in the field of eHealth. Several key components exist to support the ambition of a fully digitized healthcare system:

- High level of IT maturity in the population
- Personal identification number with swift development of eID
- Longstanding tradition for health registries and databases for medical clinical quality
- Danish health data network (Dansk helsedatanettverk) provides secure digital connection
- Advanced legal framework

The implementation of EMRs dates back to the 1980s. The first national eHealth strategy came in 1996. Throughout its history, Danish eHealth strategies have shifted from plans for a top down development of a national EHR system, towards a more organic, bottom-up approach in which implementation is tuned to technical and cultural developments in the technology market and the healthcare system.

#### ***Timeline***

**1994:** Public enterprise [MedCom](#) is founded with operative responsibility for the national health net (Sundhedsdatanet), databases/registries, standardization/testing/certification, information security, and deployment of selected national initiatives.

**1996:** *Handlingsplan for EPJ* (Action plan for EHR) launches a series of pilots in the hospital sector which revealed the need for data sharing across units in and between hospitals, consequently illuminating the need for standardization. Sundhedsstyrelsen was commissioned to design national standards.

Meanwhile, the counties started implementing EMR systems. Rather than opting for a single system, each county engaged in an individual procurement process. The decision was influenced by their negative experiences with a shared PAS system (“Kommunedata”) and a monopoly-like situation which was considered both costly, low on functional flexibility and leaving them with little influence with the vendor. The hope was that competition would improve the quality of the end product. In addition, policy makers were keen to avoid a monopoly situation in the EHR market. Three trends emerged:

- Procure existing systems (mainly Swedish) in order to be part of a community of other users. Systems that had some years of use experience, but that only showed EMR from one unit.
- Develop a record system on top of existing systems (PAS, lab, etc). Results in high level of integration between work processes, but dependency to *one* vendor.
- Opting for modern technology, which meant development from scratch since product did not exist in market – involved long and risky development process.

**2000:** The recognition of the complexity and risks involved in hospital EHR projects was growing. Many hospitals were reluctant to initiate EHR projects, and deployment was slow.

Start of SUP project (standardiseret udveksling av data). The aim is to extract vital data from local EMRs and store these in a central database according to a common method that made them available in a web browser.<sup>22</sup>

**2001:** Sundhedsstyrelsen publishes *Grundstruktur for EPJ – G-EPJ* («Foundational structure for EHR»). What was originally intended as an exchange format had become an information model for EHR Systems. The model was completely different from the existing free text based systems, and also required the user to document in a problem-oriented fashion –that is, taking diagnosis as the starting point – rather than chronologically.

No existing system in the market could deliver according to these standards. Three pilots were initiated to test the G-EPJ model. During the annual budget negotiations, it was agreed that all hospitals should implement EHR systems within 2005. The capital county and the city of Copenhagen engaged in a collaborative project to develop an EHR system G-EPJ model. In sum, this meant that within 2, 5 years Denmark was to test, develop and implement EHR systems based on the G-EPJ standard throughout the entire hospital sector.

**2002:** SUM, Danish Regions and Kommunernes Landsforbund establish [Sundhed.dk](http://Sundhed.dk), the national health portal providing general health information as well as individual health information for providers and citizens.

**2003:** The Danish Health Net is established by MedCom.

**2006:** The Capital/Copenhagen project is cancelled. *Den Nationale EPJ-organisation* (“The National EHR-organisation”) is set up as a joint effort between central government, the Danish Regions and Kommunernes Landsforening with the aim of securing national deployment of EHR systems.

**2007:** Commissioned by SUM, Deloitte releases the evaluation report [Strategiske udviklingsveje for epj](#) (In Danish) on the status on the Danish EHR development.<sup>23</sup> The analysis states that deployment of electronic messages has opened the electronic communication channel between hospitals and GPs. The development of sundhed.dk has established an important framework for the communication between citizens and the healthcare system. However, the (international) health IT market is considered immature with regard to developing systems that can meet the specifications of the G-EPJ model.

The report points to the need for more integrated care, and thus recommends stronger commitment, coordination and control with the eHealth development across the three levels of the healthcare system. In response, the National EHR-organization changes name to *Sammenhængende Digital Sundhed i Danmark – SDSD* («Connected Digital Health Denmark»). The purpose of SDSD is to

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<sup>22</sup> The SUP project is the start of what later is to become the national eRecord.

<sup>23</sup> The work on the report is organized according to eight streams. 1) Governance, organization, financing, 2) Value for the citizen 3) Clinical use and value 4) communication across the healthcare system 5) Clinical infrastructure, including terminology, classifications and process model 6) Patient trajectories, statistics and quality data 7) IT architecture 8) Vendor strategy and market for EHR solutions, including market maturity.

develop and deploy an IT strategy for the healthcare system and secure the development of a national IT architecture and IT infrastructure according to shared standards in collaboration with government, hospitals and municipalities and other stakeholders. The change signifies a strategic shift for Danish eHealth towards a focus on integrated care enabled by access to record data across the healthcare system.<sup>24</sup>

**2008:** SDSD launches the fourth National eHealth strategy [Sammenhængende Digital Sundhed i Danmark - Nasjonal strategi for digitalisering af sundhedsvæsenet 2008-2012 - Til fremme af befolkningens sundhed samt forebyggelse og behandling](#) (In Danish). The strategy, and the chosen concept, is grounded in an evolutionary perspective on eHealth (page 2):

*The Plan is to build shared national solutions in relevant areas – in line with the maturing of those areas. ... The expectation is that as a result of the forthcoming development and deployment processes in the regions and municipalities, a selection of sustainable solutions will win their ground and spread to the other regions and municipalities. (Our translation)*

The choice is of a demand driven, iterative strategy, with step-wise, experience-based development and deployment based on existing solutions rather than the development of a new national EHR system. While ambitions should remain high, the timeline should be realistic. Local innovation would be defined as shared projects, and highly recognized project tools were to be implemented making it easier to cancel unviable projects at an early stage, without risking national harm. Sustainable solutions would thus grow to national scale according to a process of natural selection. Negative as well as positive experiences were to be broadly shared. Work at national level was to focus on the development of a shared infrastructure, a select number of shared services, and a set of shared minimal demands that each actor has to fulfill. Procurement of shared solutions should be restricted to the few areas where solutions are considered mature. The strategy is sensitive towards rapidly changing contextual conditions and recognizes that the eHealth project will be a continuous process of achieving milestone rather than reaching a final goal. The strategy is thought to secure flexibility and adaptability in the long term.

For the execution of the strategy, four actions plans were launched:

1. Solutions for healthcare professionals to stimulate quality and productivity
  - Shared Medicine Record (Fælles medisinkort)
  - National Patient Index
  - National Clinical Guidelines
  - Single sign on – efficient access to IT- systems
2. Better services for the inclusion of patients
  - Citizens' access to record

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<sup>24</sup> The idea of a national patient index was born, a solution pointing the user to relevant sources of information which can then be requested to message the information to the user.

- Telemedicine
3. Shared infrastructure and IT architecture
    - Construction of a national service platform consolidating on best practice cases
    - Enhance the national health net to increase operational security
    - Infrastructure for telemedicine and patient index – strengthened to build capacity for sharing data, information security and privacy streamlined in all projects
    - Content standardization to secure interoperability, establish national network for coordination of clinical content in IT systems, and a pathfinder project for resolutions regarding use of international standards.
  4. Digitization locally and collaboration across
    - Governance – strengthen coordination of planning and investments, monitor development and support national collaboration.

**2010:** The National Audit Office criticizes SDSD for failing to secure national deployment of EHR systems in the hospital sector. Also the Danish regions are critical towards what is perceived as a lack of national initiative and as a protest establish [Regionernes Sundheds-It - RSI](#) (The Regions eHealth).

RSI and SUM agrees on a governance model to speed up coordination and implementation of eHealth. Central government is responsible for overall development and national coordination and prioritization. The regions are responsible for investing in and implementing specific eHealth solutions. The RSI budget is negotiated with SUM through the annual budget conference. The RSI advisory group - IT5 - is assembled by the five regions' IT directors. The aim is to ensure tight integration between strategic decision making and operations.

The focus for the regional strategic collaboration is on *Clinical IT-workspace, Optimizing hospital enterprise, Integration and collaboration, and Patient empowerment*. An [indicator system](#) (In Danish) is introduced to monitor the development. Target objectives included:

- Easy log in for all hospitals within 2013
- Digital overview pictures at all acute departments within 2011
- Digital exchange of x-ray images within 2012
- Citizens' access to data in the eRecord within 2010

In accordance with the National strategy, the objectives are to be realized through collaborative projects. Aiming to develop a national infrastructure and shared services all regional projects must comply with national guidelines issued by SDSD.

Rather than *one* national EHR system, the aim is to consolidate on one EHR system within each of the five regions while the eJournal (eRecord) should enable information sharing between hospitals.

**2011:** Kommunernes Landsforbund establishes KombIT to represent the municipalities work with coordinating shared ICT needs and portfolio.

**2012:** SDSD cease to exist and [Nasjonalt Sundhed-it - NSI](#) (In Danish) ("the National eHealth Authority") is established as a subordinate branch of Statens Serum Institut (SSI). NSI is responsible for:

**Strategy and governance** – develop national eHealth strategy and collaborate with the Regions and Municipalities. Service [the National Board of eHealth](#) which advises the Government on eHealth related issues.

**Development and ICT operation** - responsible for stable and efficient ICT operation and development of eHealth systems and registers in the national infrastructure. Manages contracts with private providers, consolidates the portfolio and delivers a uniform data basis.

**Standardization** – sets national standards for eHealth and administrates an online standard catalogue. Draws up [reference architectures for collecting health data from citizens](#) (In Danish) with the aim of creating a coherent data and ICT architecture for the Danish healthcare sector.

Current strategy period

Despite long term efforts, and notwithstanding the many results of the Danish eHealth system, a recent evaluation of the 2007 structural reform points to the potential for improvement in several areas of the ICT domain. In particular, challenges of realizing actual use of the ICT systems, lack of cross-sectorial communication due to insufficiently (use of) national standards, lack of transparency about decision basis and about the progress and status of projects, and a need to realize benefits in everyday practice. It is suggested that:

- National eHealth Authority and regions must speed up development of a shared ICT infrastructure for the healthcare sector and ensure that regional and local projects adhere to national standards.
- The regions should put more priority to joint procurement, development and operation of ICT.
- The National Board of eHealth should enhance its role for the overall coordination of eHealth.

In 2013, SUM, KL and DR together launch [National strategi for digitalisering af sundhedsvæsenet 2013-2017](http://www.ssi.dk/Sundhedsdataogit/National_Sundheds-it/~media/Indhold/DK-dansk/Sundhedsdata_og_it/National_Sundheds-it/Om_NSI/SDSD_Strategi_2008_12.ashx)[http://www.ssi.dk/Sundhedsdataogit/National\\_Sundheds-it/~media/Indhold/DK - dansk/Sundhedsdata\\_og\\_it/National\\_Sundheds-it/Om\\_NSI/SDSD\\_Strategi\\_2008\\_12.ashx](http://www.ssi.dk/Sundhedsdataogit/National_Sundheds-it/~media/Indhold/DK-dansk/Sundhedsdata_og_it/National_Sundheds-it/Om_NSI/SDSD_Strategi_2008_12.ashx) [/\(English version\)](#). It is recognized that the full benefits of digital workflows and processes across the healthcare system can only be harnessed if everyone involved takes part. Therefore, full deployment and consolidation of IT systems across the healthcare sector is the main aim, implying phasing out paper. Fewer projects should be launched and focus should be on harvesting the benefits from ongoing initiatives.

The strategy envisions using telemedicine to enable new forms of patient-centric healthcare services for the citizen, making resources available for the strengthening of patient treatment, and enable prioritization of those most in need.

The strategy points to a paper free, singular EHR system environment for healthcare personnel in which data and digital solutions are increasingly used to support workflows, planning and documentation in hospitals. Fully utilized clinical workstations and the implementation of a shared pre-hospital health records are key objectives.

Municipalities will target digital solutions to support standardized registration and coherent workflows deploying the Fælles Sprog III (Shared language III) project in all municipalities. It will be decided how the data from municipal healthcare services is to be made available throughout the sector.

ICT should increasingly be used to demonstrate the development and results of ICT in health, and the ongoing work with developing coherent patient trajectories. The aim is to move from a focus on gathering, storing, and giving access to data, towards a focus on improving use of data with tools that can be used in everyday clinical practice, including data coming from patients. An overall framework for secondary use of data is to be developed, with SSI as responsible for securing, storing and sharing of data. The challenge is to provide health professionals with a knowledge intensive basis for decision-making. Digitalization efforts should provide support for rapid deployment and implementation of national guidelines on clinical workstations or through apps.<sup>25</sup>

With several rapid, large scale changes on the way, eHealth governance is seen as key, which includes making clear goals and a clear division of responsibilities, along with actual capacity to implement the changes and transparency about progress and results:

The regions are responsible for ensuring efficient and effective eHealth at all Danish hospitals, including responsibility for procurement, development and operation of ICT solutions as well as for optimal ICT solutions in support of workflows and patient treatment.

Central government will be responsible for determining the legal framework and standards for use of the ICT, for ensuring that relevant data is shared across the healthcare sector, as well as for realizing cross-sectorial ICT projects and national infrastructure.

In addition to the (2010) agreement between the regions and SUM, in this strategy period the municipalities will be included and will follow the same basic principles.

The National Board of eHealth will serve as the hub for central-, regional- and local-government collaboration and is responsible for:

- realizing the initiatives set out in the annual budget agreements
- following up on realization of the initiatives in the national strategy
- monitoring other strategically important projects
- overall coordination and prioritization of efforts
- follows up on progress
- corrective action with regard to priorities and goals for efforts

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<sup>25</sup> There is a broad consensus regarding the need for electronic national clinical guidelines in Denmark. Several different approaches have been tried since the mid-1990s, but have so far been unsuccessful. The latest attempt in 2009–2011 was to convert the IT platform and clinical content found in the English system “Map of Medicine”, but the attempt was met with significant resistance from the medical community and the Danish regions because it did not meet expectations in terms of content and cost.

- addressing cross-sectorial challenges
- setting up a project portfolio steering committee to ensure progress, coordination and stability of delivery in the implementation of selected public-sector projects with critical dependencies, initially including: Shared Medication Record; Deployment of MedCom standards; National Service Platform; Clinically integrated home monitoring; and National Health Record.<sup>26</sup>

The national eHealth strategy is to be further detailed out in the annual budget negotiations and concretized in Action plans continuously developed, updated and monitored by the NSI.

2013 was also the year for the launch of the first collaborative RSI strategy [Sammenhængende, effektive og ensartede digitale muligheder \(2013-2019\)](#) (In Danish). The strategy signals a shift from activity based planning towards a quality-oriented agenda. Key is the development of integrated and efficient patient pathways to minimize mistakes and maximize patient satisfaction. ICT is both envisioned as a part of the solutions integral to increasing quality, and a supportive mechanism throughout the change-making processes necessary to realize the quality agenda. Lesson learnt since 2010 is that it is not sufficient to gather data, data needs to be translated into tools that support coherent patient trajectories, cross sectorial communication and decision-making. It is realized that regional collaboration is not enough; there is a need for a shared national infrastructure integrating processes across the levels of the healthcare sector. Strategic objectives and related milestones are to be detailed out in biennial documents developing shared understanding of deadlines, standards, functionality and service targets, and procurement.

As a part of the 2013 regional and municipal budget agreement, a governance and financing model for operation and further development of public sector eHealth was established. This financing and governance model will be the framework for stronger collaboration on eHealth in the public sector. In 2014, the model will cover the National Service Platform infrastructure component, as well as the Shared Medication Record.

Having introduced the broad framework for Danish eHealth and its history, we move on to describe the current Danish eHealth system.

### **3.6 Current National eHealth System**

The national IT-architecture describes shared principals for the digital solutions. The architecture should make it possible to offer services to others in a uniform way, with a uniform access control system. The architecture should be the foundation for new solutions that are to be fitted into the

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<sup>26</sup> As a general rule, the committee will solve tasks and challenges at the lowest possible level, which is in the relevant project's own steering committee and/or in the project organizations implementing the project. The project portfolio steering committee will ensure clarity of commissions for project implementers, including ensuring harmonization of any conflicting requirements and requests for the development and timing of solutions within specific goals and budgets. Implementation efforts also need to be made more uniform and the health services agreements should be used to boost implementation efforts locally.

existing solutions and should make sure different solutions are working functionally together, mutually exchanging data. The architecture should facilitate a market for vendors.

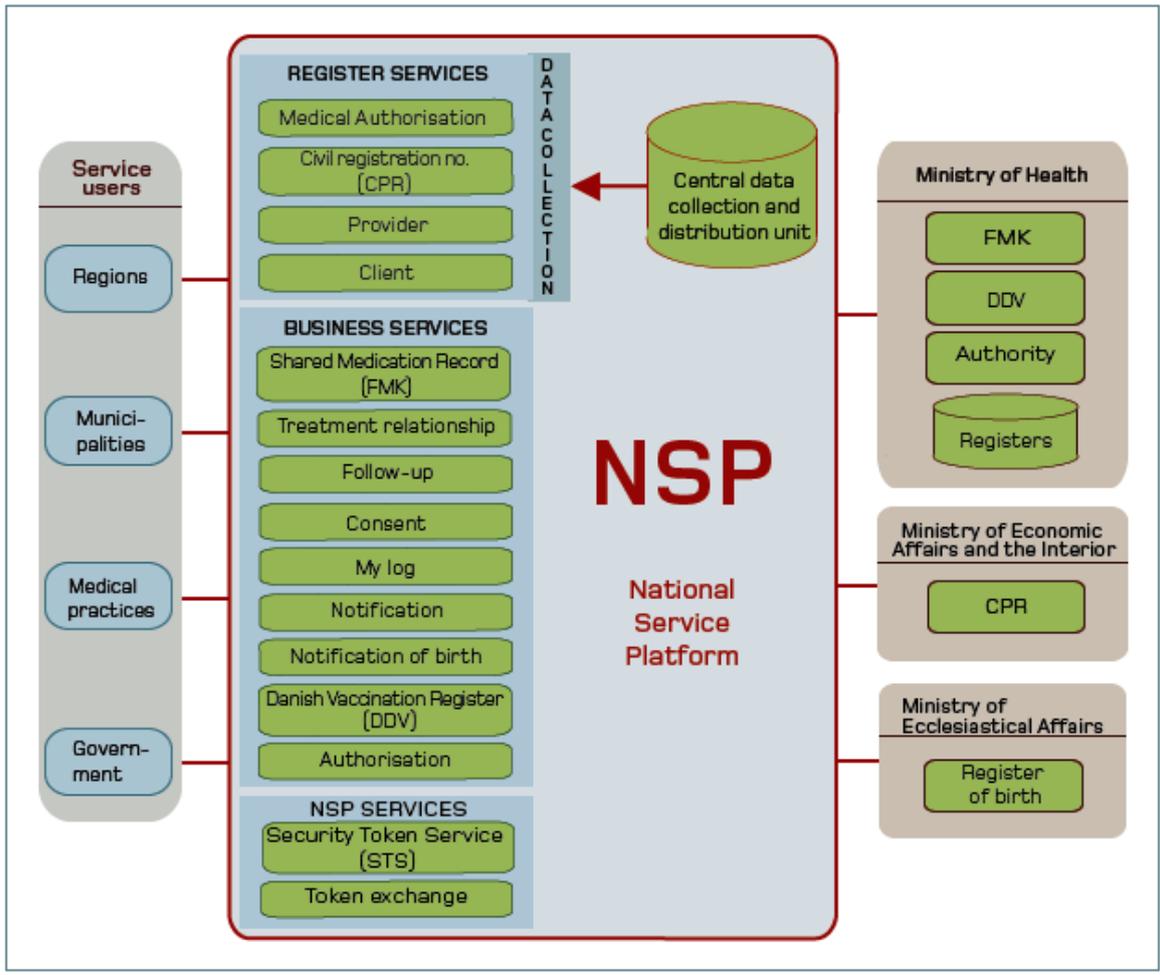
### 3.6.1 Infrastructure

The Danish eHealth infrastructure consists of a national IT-architecture, the national health net, the National Service Platform, and an electronic portal providing access to data.

[The National Health Net](#) (In Danish) is operated by MedCom. The health net is a secure infrastructure connecting the actors in the healthcare system offering XML and EDIFACT message exchange service, index based search in external databases, exchange of pictures, and videoconferencing services. Sundhed.dk uses the health net as connection channel to the local systems in the healthcare sector.

The [National Service Platform \(NSP\)](#) is a central hub for national data and business services in health that makes it possible to use national registers and services directly in patient treatment by ensuring the required availability and operational reliability.

Figure 4. Danish National Service Platform



Source: NSI

The national infrastructure will be extended in the current strategy period to develop a more coherent data and ICT architecture which meets the healthcare system’s different requirements for

data sharing. An important element in achieving this will be to further develop the Danish Health Data Network, the video hub, the National Service Platform and the public sector ICT security solutions. In this connection, a mobile security component will be established and there will be an analysis of security standards and security solutions in the healthcare sector.

The common ICT infrastructure and standards will be incorporated into all relevant ICT projects. The further development of the data and ICT architecture will have to be balanced with the needs arising from strategically important projects such as the Healthcare Platform project in the Capital Region of Denmark and Region Zealand, as well as the large telemedicine projects.

[Sundhed.dk](http://Sundhed.dk) is the official portal for the public Danish Healthcare Services and enables patients and healthcare professionals to find information and communicate. It is also the portal for patients to access information from their own EMRs.

### 3.6.2 Infostructure

NSI is responsible for national standards (including data standards, classifications and interface standards) for the use of ICT in the healthcare sector following consultation with the National Board of eHealth.<sup>27</sup>

Work involves a Danish translation of SNOMED CT, NPU terminologies and NBS – Det Nationale Begrebsarbejde for Sundhedsvæsenet. NSI also develops the sectors classification system (SKS), hospitals classifications (SHAK) and the register for healthcare organizations (SOR).

NSI is working with reference architecture that describes the central parts of the content in EHR systems. The model is specified in the form of UML information models and belonging XML forms. The aim is to support clinical processes and the focus is on the steps in this process: Problem/Need/Diagnosis; Aim/Expected outcome; Action/Intervention; Result/evaluation.

### 3.6.3 Privacy, Information Security, Access Control

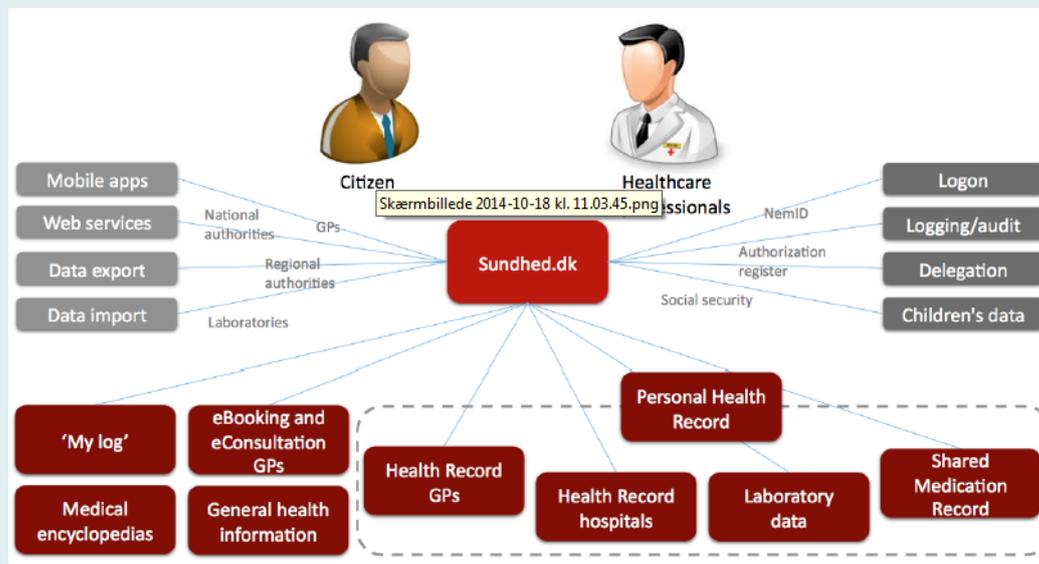
Sundhed.dk provides access to the healthcare sector's shared data for citizens and professionals. The portal uses a public-key infrastructure (PKI) for security. Access by patients requires a digital signature (NemLogin). Patients store the digital signatures on their personal PCs and can also transfer them onto thumb drives if they wish to access the portal from another PC. Access by clinicians or pharmacies requires special security certificates. Patients can view the name of the person viewing their data, the date and time of the access, and the action taken.

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<sup>27</sup> [National standard catalogue for ICT in healthcare](#) (In Danish).

### 3.6.4 Shared eHealth Components and Services

Figure 5. Shared components and Services



Source: Sundhed.dk

[MedCom messages](#) (In Danish) cover the most frequent text-based clinical messages between healthcare professionals such as discharge letters, referrals, lab test orders, e-prescriptions and reimbursement from public health insurance. The messages include codes, among other things for standardized pathways.<sup>28</sup>

[Henvisningshotell – REFHOST](#) (In Danish) (Referral note hotel) was developed by MedCom and put to use in 2008. The basic idea is that GPs referrals to specialists, physiotherapy or psychologist can be sent electronically to the referral hotel – REFHOST. The patient can then choose which provider to obtain the service from. The referral note is kept in REFHOST until the patient has chosen a provider that can obtain the referral note through the local EMR system.

[Sundhed.dk](#) was established in 2003 by SUM, DR, and KL. The portal is the digital access point to the Danish healthcare system. The portal provides official information about healthcare rights and services. In a secure part of the portal, patients and professionals can access personalized health information. According to the [2013-2015 Strategy for Sundhed.dk](#) (In Danish) 80 % of the communication between citizens and the healthcare system should become digital. Healthcare personnel with treatment responsibility can log on to Sundhed.dk to access health information including the eRecord (see below), Fælles Medicinkort (see below), lab results, and data on treatment of selected chronic patient groups. Sundhed.dk is a supplement to local systems, with information that is not documented, stored or in other ways made available via the local systems. Sundhed.dk also offers access to a range of administrative services for healthcare providers,

<sup>28</sup> <http://medcom.dk/wm109919> (In Danish)

including information about the tariff system, waiting time, registration of sickness leave, as well as guidance to use of shared IT systems.

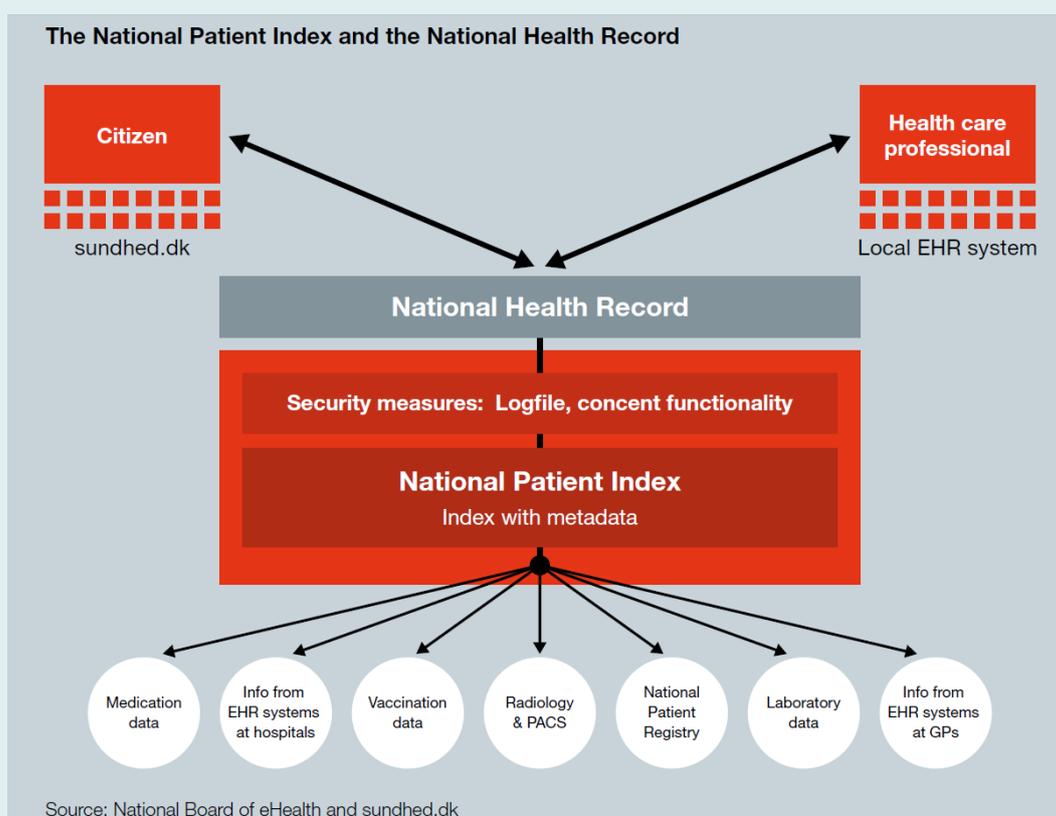
[eRecord](#) (In Danish) is the national repository of record information from all public hospitals in Denmark and GP records (currently not in service).<sup>29</sup> The eRecord includes data on diagnosis, treatment and visitation notes. About half of the hospitals also provide information about medication and test results from the laboratories. Hospital employees have access to the eRecord through their EHR system, GPs and patients access via sundhed.dk.

The eRecord was originally (2008) thought of as one out of two interlinked projects - **the National Patient Index (NPI)** and **the National Health Record (NHR)**. NPI was an infrastructure project to enable search for existing patient data in the data sources integrated in the index (See figure 6). The national health record, was to be an expansion of the eRecord, displaying data from the data sources in the national patient index in a coherent and intelligent user interface. The aim was to provide healthcare personnel a robust basis for decision/process support. In 2013, the project was cancelled after having spent 16,5 million DK. NPI was to recycle interfaces of existing data sources. However, most sources had not established mechanisms for event-based updating of the index. Different solutions were explored, but they all proved to be far beyond the economic frames of the project.

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<sup>29</sup> No longer in service due to problems with adherence to Danish data protection regulations.

Figure 6. Illustration of original plan for development of National architecture for eHealth



Sources: Sundhed.dk

[Fælles medicinkort - FMK](#) (Shared Medication Record) gives citizens and healthcare personnel access to information about medication and vaccinations, with the possibility of registering and editing. Access to FMK is provided through integration with the local EHR systems of GPs, hospitals, home care, and others. The service can also be accessed online. Citizens can access Fælles medicinkort through online log in, or Sundhed.dk. The citizen can view prescription and vaccination information (2 years).

The Shared Medication Record was fully implemented at all hospitals and general practitioners in 2014, several years overdue. In a recent [report from the Danish National Audit office](#) (In Danish), the project receives heavy criticism.

### 3.6.5 EHR Landscape

In the Danish EHR landscape there are five regional system environments, three municipal electronic care record system vendors and about ten GP system vendors. The variety of system installations is described as a challenge for the rate of introduction and cost-effectiveness of eHealth development.

When the regions took over the ownership of the hospitals in 2007, they also inherited a fragmented portfolio of IT systems, many of which were enterprise critical. The regions have since invested hugely in consolidating their IT systems and preparing for a shared record system, for instance by developing single-sign on or portal solutions that gives the user an overview of all relevant patient information from different subsystems, while also worked to broaden access to IT system for all professional groupings.

In the municipal healthcare system, health data is today primarily recorded and registered in electronic care records systems as well as in municipal child-health records systems. An essential challenge will be to provide better support for patient pathways and for the delivery of municipal healthcare services, including homecare and home nursing services. Better data is needed that can enhance and standardize the quality of services, as well as data that can ensure systematic documentation in municipal efforts. At the same time, the digital solutions in support of workflows and processes in the municipalities have so far been aimed at recording and documenting activities, while less focus has been afforded to digital support of coherent workflows and data sharing. More specifically, this means that for example nurses have to enter and retrieve data in long text documents using free-text search. There are only a limited number of registration standards for data about patients' blood pressure, body temperature, well-being, etc.

### **EHR development - an example from the hospital sector – “Sundhedsplatformen” at Region Hovedstaden and Sjælland**

In 2011, the Capital region together with the Zealand region decided to depart from the strategic course agreed upon in the RSI collaborative platform. The two regions launched plans for a commercial procurement of a New IT platform with EHR and PAS functionality, and later chose EPIC as the vendor. The IT platform will serve 2, 5 million inhabitants, 44.000 users and 20 hospitals. The platform is currently being implemented and the plan is to have it ready for use in 2016, with full implementation in both regions within the end of 2017.

The procurement signifies a shift from a «best of breed»-strategy which had led to a portfolio of 1.200 ICT-systems and a heterogeneous operative environment that was experienced as complex and expensive to operate and a barrier to interoperability.

The main objective for Sundhedsplatformen is a paper free working environment for health care personnel and solutions that put the patient in the center. The regions found themselves in a situation with an increasing need for ICT solutions that support work processes across place, level and disciplines. An assessment process in the regions concluded with that ICT supported coordination of care would best be enabled by gathering data in one system and use these continuously for decision support, research and quality improvement.

With regard to size, the project is described as a top five implementation for the largest international EHR vendors. The procurement project which ran for about two years had a prize for 20 million DKR. The implementation project has a budget for 1, 3 billion DKR. This does not include the costs associated with personnel and training of staff. The Capital region has invested 75 % and the Zealand region 25 % of the budget. Even through the coordination between the two regions' processes is described as demanding, a shared procurement gave a significant better deal than what would have been if the regions were to sign two separate contracts. The project is described as resource demanding to the extent that it would not have been possible for one region to do on its own.

A program for procurement and implementation has been established with 310 employees. The program director is from the Capital region, which is responsible for budgets. The governance model distributes a 50/50 decision making share among the two regions, and contains no elements of national steering.

In the process of choosing a vendor a product test was organized. 12 patient trajectories were described, which the vendors were invited to run their programs through. 450 clinicians took part in the selection of the system. In addition, a test lab was used in which 18 clinicians trained with the vendors and evaluated the systems.

The choice of vendor was largely influenced by the regions former experiences with poor implementation processes. The regions were looking to buy an implementation partner, as much as an ICT system. That meant a vendor with a solid methodology that could manage to engage the organizations in a shared learning process.

Epic is sole responsible for implementation, and do not use an implementation partner. The program management describes it as unproblematic to use an American vendor since US is a reference country for clinical and healthcare practices both in general, and in the area of eHealth. The collaboration with Epic is estimated to last for 15 years, with implementation of different versions throughout the years. The program is still negotiating the content of different versions.

The procurement is primarily for the hospitals in the two regions, with options for other regions. The other regions are currently not planning to buy into the contract, as they have recently made considerable investments in the development of their own ICT solutions.

Sundhedsplatformen shall support the Danish quality model both through standardizing patient trajectories and automatic reporting. Even though the product is off the shelf, all clinical content needs to be built, adapted and validated according to Danish standards. To prepare for the implementation, a large disciplinary standardization process is ongoing in which 400 clinicians are involved to secure optimal and harmonized work processes on the basis of evidence based practice.

The two regions experience that the program is very resource demanding, and also that it demands a lot with regard to management focus. The program has initiated a dialogue with national authorities to communicate that it is difficult to commit to other national eHealth projects while the implementation process is ongoing.

As is, the implementation has not required amendments in national laws and regulations. However, the program is working with national authorities to make existing regulation more precise. The ICT system now under implementation requires a more precise definition of terms than found in the existing legal framework for eHealth.

### **EHR development - an example from the municipal sector – Copenhagen Municipality**

Up until now, the ICT effort in Danish municipalities has to a large extent been about digitization of documentation processes, while less focus has been on ICT mediated coordination of care and data sharing. According to the joint national eHealth strategy, there is a need for better data can be used to improve and standardize the quality of services, and systematically document the ongoing activity in the municipal sector.

Copenhagen municipality points out that national authorities thus far have not had a focus on standard development for municipal health and care services, nor for the collaboration between primary and specialist health care. The result is that municipalities have adopted hospital standards where this are considered relevant, and for the rest do not have structured information. As a result,

the users have to spend a lot of time looking up information based on free-text searches in patient journals.

The RSI indicator system for deliverance and results is an important political statement in the ongoing Danish debate about shutting down the regions. The municipalities have thus far not been exposed to the same form of demands for delivery from the state.

The municipal effort in the eHealth area has traditionally been project based – many projects and pilots, often targeting small, or idiosyncratic patient groups. However there are signs that this is now changing. SUM points out that the municipal reform from 2007 laid the groundwork for the municipalities to become large enough to handle larger administrative tasks. This has also been well received by the municipalities, also in the area of eHealth. According to SUM, this preconditions that the municipalities take on more responsibility for developing larger, joint projects that contributes to establish a coherent national architecture, and that the municipalities reports data that provides insight into the development.

As part of professionalizing their eHealth activities, Copenhagen municipality had developed a system for prioritization of projects. Staking as the starting point the municipality's strategic plan for eHealth, the municipality is mapping what effects specific efforts have for strategic goal realization and status for these. The mapping illustrated where it is most efficient to invest efforts in order to reach the strategic objectives. The purpose of this work is to facilitate political and operative prioritization of efforts.

A decision has been made among all Danish municipalities to implement a care plan. Copenhagen municipality has taken the lead role for the project and is working on the specification of needs and probing the vendor market. The project looks to the international vendor market, where work on standardization has evolved farther than in Denmark. The project is looking for a product with documented quality. The municipalities experience that many of the EHR vendors are rather skeptical about entering the municipal service area because of its size and complexity, and the lack of standards. As part of the care plan project the municipalities are looking to products both from EHR vendors and products from the general ICT market. Copenhagen municipality is among other things exploring the possibility for creating links between logistical systems and programs for competency building. As an example the project is envisioning a solution that combines surveillance of ulcer sores ratio with distribution of information on preventive work and treatment for this condition.

### **3.6.6 Digital Services for Citizens**

In a secure part of sundhed.dk, and more recently through Denmark's citizen's portal (borger.dk), citizens get an overview of consultations with the healthcare system, including treatments received at a hospital. They can also access their health information, including hospital records (eJournal), Fælles Medicinkort, and the GP record (P-record) (currently not functional). There is a log of who has accessed a patient's record, and what information they have been seeing. Patients can book their appointments with the GP and change GP.

Sundhed.dk also gives access to information on waiting times at all public hospitals and ratings of hospitals in terms of patient-experienced quality and service. Through the portal, the citizen can get involved in patient networks with the possibility to discuss their own disease, treatment and more with other patients with a similar diagnosis, which is considered especially relevant for patients with

a chronic disease. Citizens can access a patient handbook, a service directory, and general information about healthcare services and rights.

In 2011, a strategic decision was made for Sundhed.dk to primarily support communication between the healthcare system and the citizen in situations in which the patient is in, or on its way in, a patient trajectory. In other words, serving the information and communication needs of patients is priority, rather than the general information needs of citizens. The objective is to enable patients to take on a more active role in their own treatment and care, also in their own home, for instance by allowing patients to upload data from home monitoring devices to the platform. The decision should lead to further consolidation of Sundhed.dk as the connecting point for digital health information and communication, and higher degree of deployment. What is more, communicating this decision should lead to balance expectations for partners and users. The national strategy states that within 2015 80 % of all referrals, reporting, formal letters and other written communication between individual citizens and the healthcare services will be digital.

Through digital dialogue, patients' can get answers to short and simple questions in non-acute cases.<sup>30</sup> The current national eHealth strategy sets out the goal to increase digital communication with the healthcare services. Pilot projects on booking of appointments at hospitals will be carried out by the Danish regions. The use of text message appointment reminders will be increased in order to reduce non-attendance.

Telemedicine is a prioritized area for the municipalities, in particular in the light of their responsibility for follow-up of chronic care patients.<sup>31</sup> The [national strategic plan for telemedicine](#) (In Danish) states that diagnosis of ulcer and psychiatric treatment through telemedicine is to be fully deployed, and a national infrastructure for telemedicine established. The potential of chronic conditions patients to measure and submit information about their condition for use in organizing their treatment is to be explored. This also means clarifying responsibility with regard to the quality of the measuring devices and data they produce, as well as the use of data in treatment and care.

### 3.6.7 Secondary Use of Data

With its establishment in 2011, The National Board of eHealth is made responsible for the consolidation of national health registries and National patient registry.

SSI administers a broad range of health registries and quality data bases. [eSundhed](#) (In Danish) is the citizens' and professionals entrance point to health data, indicators and comparisons from regions-, hospitals- and municipalities. The purpose is to support clinical work and contribute to that the patients receives rapid assessment, treatment and care of high and universal quality :

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<sup>30</sup> To read more about legal foundation, security, and responsibility issues surrounding the tariff system, please see page 9 in the following document (In Danish):

[http://www.laeger.dk/portal/pls/portal!/PORTAL.wwwpob\\_page.show?\\_docname=10623108.PDF](http://www.laeger.dk/portal/pls/portal!/PORTAL.wwwpob_page.show?_docname=10623108.PDF)

<sup>31</sup> It is worth noting that Telemedicine has a broad definition in the Danish healthcare system, which also includes telecare/care at a distance.

- Support patients' free choice of hospital and give access to health quality data
- Support transparency through openness about results and access to data sharing across
- Give access to monitoring of political agreements for healthcare, such as standardised patient trajectories (pakkeforløb) and healthcare agreements between central government, regions and municipalities
- Give access to relevant aggregated health data

SSI manages eSundhed which contains an open and a secured area. The open area publishes health data at an aggregated level. The secured area is targeting municipal and regional authorities and publishes settlements concerning financing, controlling/clearing, and the underlying activity based on the DRG-system. The system manages the practical settlements and payment streams which take place in connection with the municipal co-payment and the financing of healthcare. What is more, the system uses an analytical tool to illuminate the activity behind the financial settlements. In the secured area of eSundhed it is possible to access health data on an aggregated level and individual level.

As part of the current national eHealth strategy, [Statens Serum Institut](#) has been given the responsibility for developing an overall framework for secondary usage of health information. In general, the trend is a shift from a focus on collecting data and making it accessible, to a focus on developing tools that use these data to enable a more knowledge intensive practice.

### **3.7 Final Reflections**

A key characteristic of the Danish eHealth system is the ongoing joint efforts between the main public actors; the State, DR and KL. We have seen that this involves both strategy making, ownership of key organizations such as MedCom, and the execution of national eHealth projects. It is thus interesting to look into experiences with this form of joint responsibility.

We have not been able to find evaluation reports discussing this matter in general. However, in 2014 the [National Audit Office \(NAO\)](#) released a report on the Shared Medication Record (SMR) project - the largest collaborative project since the signing of the Health IT agreement in 2010. The report points to several challenges and recommendations for improvement with regard to the management of a large-scale eHealth project.

The background for the NAO investigation was several delays in the SMR project. NAO wanted to look into whether the Ministry of Health, NSI and the five regions had made an adequate effort to develop and implement SMR. NAO found that the effort made by the Ministry of Health, the NSI and the regions to develop and implement the SMR had been inadequate in crucial respects. As a consequence hereof, the SMR program was considerably delayed and important issues remained unsolved.

NAO finds that the system is not being much used following implementation, and that all planned sectors have not yet been linked to the SMR. Several independent public and private parties are involved in the SMR program, which increases the need for effective program management. When the framework of the project was defined, however, neither the Ministry of Health nor the NSH adhered to the principles for good practice concerning anchoring of the program in the top management. Moreover, the benefits and costs related to the program have not been clarified and it has not been sufficiently clear what the parties were required to deliver and when. Significant

weaknesses in the program management performed by the Ministry of Health and the NSH, including inadequate follow up on program risks, on the development in total costs, on the realization of benefits and on delays. Overall, lack of managerial power, incentives and knowledge of the status of the program has impeded progress.

The Ministry was criticized for not sharing information about the challenges with roll out in the municipalities, and the outcome of pilots showing that the integration of the system did not succeed as planned. NSI had neither mapped the work processes that the SMR was designed to underpin, nor tested the usability or the quality of the data sufficiently before attempting to put local SMR integration into full operation at hospitals and GPs. Prior to this, the steering committee had decided to maintain development and implementation of the system nationwide without carrying out further pilots, despite the fact that the pilot that had been carried out had failed to demonstrate that the SMR would work for daily operation for all relevant groups of health professionals.

As regards information security, NSI had not adequately secured the central SMR system. Thus, the NSI had not established sufficient supervision of the regions' administration of access to sensitive personal data on the citizens' medication in the SMR. The regions had failed to establish essential preconditions for successful implementation of the SMR. For instance, the regions have failed to ensure that the medication records are "cleaned up" so that they can provide the healthcare professionals with correct information about the patients' medication. Nor had the regions taken appropriate steps to ensure that the users knew how to use the SMR, this involved lack of training and lack of usability testing.

On the basis of the findings, NAO made the following recommendations for future national scale programs:

- Based on the Danish joint governance model's recommendations concerning governance, the governance of a program should include those parties that are paying for/contributing to and benefitting from the program.
- The benefits and costs derived from participating in the program should be clarified in order to establish incentives for achieving the common targets. The parties' responsibility for delivering individual elements of the program should be defined and converted into measurable milestones with realistic time frames. The parties should commit to delivering on time and procedures should be in place to follow up on deliveries.
- Long-term programs should – in compliance with the recommendations of the Danish joint governance model – be reviewed regularly, for instance every six months, to provide clarity of progress, use of program funds, etc.
- Before digital solutions are rolled out for general usage, their usability should be confirmed through small-scale testing.
- Efforts should be made to ensure that the users know how to use important digital solutions correctly and with ease; for instance, the users could be required to pass a test, and the user-friendliness of the solutions could be tested before implementation.

## 4 Finland

### 4.1 Demographic Data and Political Tradition

Population (2013)	5 439 407
Area (km <sup>2</sup> )	338 424
Political tradition	Parliamentary republic
Administrative levels	State, region, municipality

### 4.2 Key Figures for the Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	80.5
<b>Expenditure on health</b>	
In percent of GDP	9
Per capita (USD purchasing power parity)	3 374
Public financing (% of total expenditure)	75.3
Private financing (% of total expenditure)	24.7
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	3.3
Practicing nurses (per 1000 population)	10.3
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	4.2
Hospital discharges (per 1000 population)	180
Total hospital beds (per 1000 population)	5.52
Average length of stay, all causes (days)	11.4
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	100
Out-of-pocket medical spending (% of household consumption)	2.9

### 4.3 Gathering Experiences and References on the Finnish Case

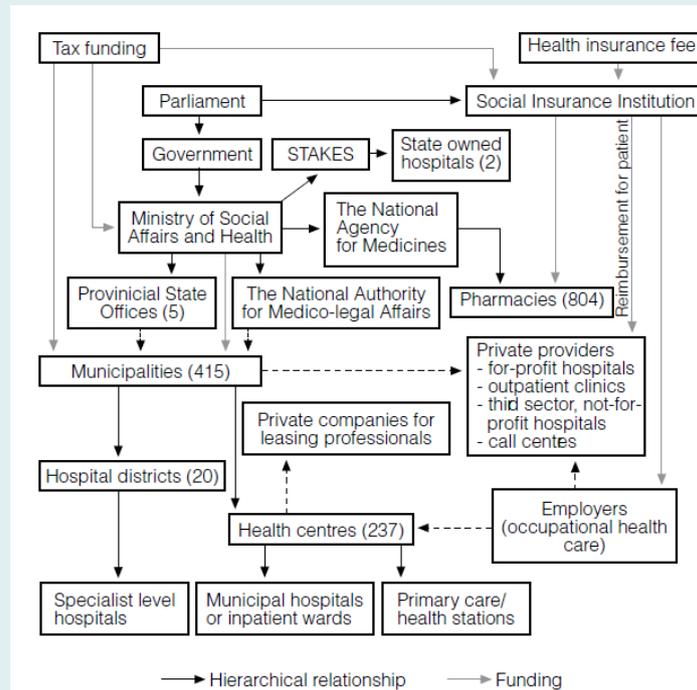
The empirical material for this chapter is gathered through:

Desktop research, May-June 2013 and January-March 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Finish healthcare system, eHealth strategy, key actors and initiatives.

In this chapter on Finish eHealth we will use the empirical material to describe the past, present and future of the Danish eHealth system. Obviously, the description is not exhaustive. The content of this report reflects the knowledge needs of the Norwegian *One patient – One record* program.

#### 4.4 Financing, Governing and Organizing the Finish Healthcare System

Figure 7. Finnish Healthcare System



Source: WHO HiT Series

Finland offers universal public healthcare services free of charge to all citizens. Health services are mainly provided by the public sector and funded by tax revenues (75 %) collected by the state (40 %) and the municipalities (35 %). The State allocates a non-ear-marked subsidy to the municipalities, depending on age structure, unemployment rate, number of pensions for the disabled, and population density. However, the Finnish system is very de-centralized and the overall funding of the system has many mixed features. 25 % is funded privately and direct out-of-pocket payments account for 19 %.

[The Ministry of Social Affairs and Health](#) has a broad mandate, directing and guiding the development and policies of social protection, social welfare and healthcare. The Ministry supervises several independent agencies and institutions that implement the social welfare and healthcare policy goals in respective areas of public health, R&D, working health etc.

There are 336 municipalities in Finland, of which more than half have less than 6000 inhabitants. Municipalities are responsible for all healthcare and welfare<sup>32</sup>, but are quite autonomous in terms of

<sup>32</sup> The law on social welfare stipulates the social services that municipalities must produce which includes preventing social problems, maintaining social security and supporting people's independent living. The obligation to arrange social care services is mostly carried out by the municipalities alone and involves a broad

how to arrange these. Some municipalities provide services while others have either formed provider cooperatives, or buy services from the private sector.

The municipalities have alone or jointly formed about 166 healthcare centers - functional units or organizations - that provide primary curative, preventive and public healthcare services. The inpatient department of a healthcare center works in much the same way as the department of a hospital. A typical healthcare center has 30 to 60 beds. The number of inpatient departments within a healthcare center varies – large centers have several. The patients are mainly the elderly and the chronically ill. However, in remote sparsely populated areas, healthcare centers provide rather comprehensive short-term curative inpatient services for the general population.

Municipalities provide long-term care in wards at healthcare centers and nonmedical long-term care in institutions for the elderly. The latter is considered a part of social welfare services.

Public secondary care and ambulance services are provided by the country's 20 hospital districts.<sup>33</sup> All municipal health centers must be part of a hospital district to guarantee specialized healthcare services at an accessible distance. A hospital district is an administrative entity that may operate in more than one location. Hospital districts can purchase services for their population from other hospital districts, the private sector or abroad.

In the public healthcare system, GPs act as gatekeepers to secondary care. Patients do not need a referral to visit private specialists at private clinics. There are over 3.000 private healthcare companies in Finland and they provide care in 6.800 units. Private healthcare mainly comprises GP practices and specialized outpatient care, which are available mainly in the cities. There are only a few private hospitals, providing less than 5 % of the bed days in the country and mostly providing only beds reserved for short-stay surgery. The majority of doctors working in the private sector are specialists or GPs, whose full-time job is at a public hospital or at a healthcare center. Since 2013, patients have a free choice of healthcare provider.

### **Demographics challenges and ongoing policy reform**

Finland is sparsely populated, in particular in its eastern and northern parts. The country has one of the world's fastest aging populations. Urbanization is leaving local authorities outside the major cities without working-age taxpayers. Urbanization, coupled with shortage of healthcare personnel, means that the municipalities are very unevenly prepared for meeting increasing demands for health and social care services, in particular in primary care.

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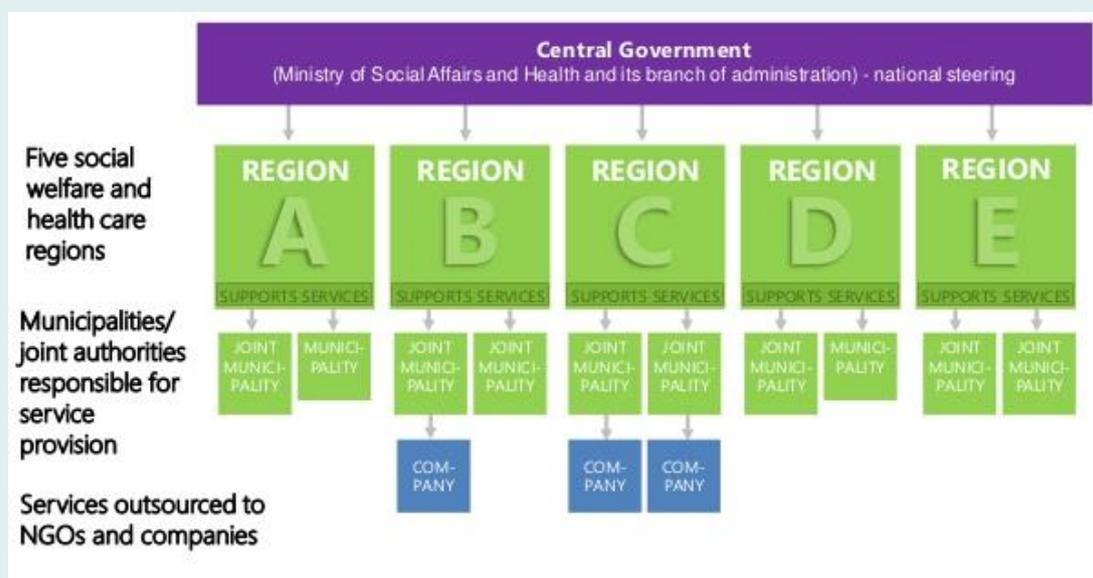
set of services from day care for children, services for disabled people, rehabilitation programs for drug abusers, etc. However, there are cases where services are arranged by federations of municipalities. Municipalities purchase several kinds of social services from private service providers. For the citizens, the social care services are viewed as public services while they are nevertheless produced by private providers.

<sup>33</sup> In addition, the semiautonomous province of Åland forms its own district.

Responding to these challenges, the Finnish government has proposed an extensive structural healthcare reform (the SOTE-reform). The 336 municipalities are organized into five administrative regions<sup>34</sup> which are made responsible for social welfare and healthcare in their respective areas.

- Decision-making and distribution of funds in each region will be centralized and supervised by one single body (the SOTE-regions) and separated from the (public) service providers (the municipalities). The result is a single funding channel for welfare and healthcare services.
- Each SOTE-region will be proportionately financed by its member municipalities.
- Service provisions will be funded by the regions.
- Every four years each SOTE-region will decide on the division of service responsibilities between the municipalities within their respective regions, the allocation of funding and resources, service structure and principles of outsources services, and quality standards.

**Figure 8. Proposed SOTE-reform; New National Health and Social Care Structure**



Source: Ministry of Health and Social Care

The main aim of the SOTE-reform is to ensure that citizens all over the country have access to the same level of healthcare and social welfare services, with the further aim of increasing the general quality and efficiency of the social welfare and reduce administrative costs in the healthcare sector. Integrating the levels of the healthcare system, and healthcare with welfare, policy makers aim to create a seamless health and social care system in which the citizen's need for services is addressed as a whole. The legislative framework for the reform is scheduled to enter into force as of January 2015. The five new regions are planned to be in function from January 2017.

<sup>34</sup> Helsinki, Turku, Tampere, Oulu and Kuopio

A SOTE-region is a joint municipal authority. The municipalities will be represented in the highest executive body of the region, based on a principle of proportionality. Central government will be strengthened. An advisory body and a steering unit for social welfare and healthcare services will be operating in the Ministry. The Ministry will have the final say on the regional healthcare planning.

ICT is considered a key enabler for the SOTE-reform. ICT should support the transition from a provider-centric, to a seamless, citizen-centric health and social care system.<sup>35</sup> In 2007, a plan for a national EHR system – KanTa - was introduced. The aim is to give citizens a wide possibility to access their health information and control its use.<sup>36</sup>

In the following we shall take a closer look at the development of Finnish eHealth system, evolving from a concept of regional health information systems towards a centralized structure for data storage.

#### ***4.5 Finish eHealth: Past, Present and Future***

eHealth has a long history in Finland. The digitization process began in mid-1980s and 20 years later EHRs were fully deployed throughout the healthcare sector.

Since the 90s content standards for EHRs were developed, while technical standards for transferring data have been developed since 2000. The principal has been to identify the most used international IT-standards within healthcare.

Since 2000 work has also been focusing on developing shared regional information systems, however, the Regional Information Systems were incomplete, as the information being exchanged was incomplete and because private service providers were not part of these networks.

The high degree of local autonomy meant that a considerable diversity of IT systems was put to use. Because of the geographically organized healthcare, in which healthcare personnel often work both in public and private healthcare organizations, personnel often had to use many different systems and interfaces, even for the same patient. The system portfolio did not support the integration of care across the healthcare system.

In the face of increasing specialization and more need for coordination of care, semantically interoperable patient records and a national concept for archiving health information has become the main goal for Finnish eHealth. Launching the KanTa project, the aim is to move from a situation of information islands, towards a more systematized approach that can support integrated health

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<sup>35</sup> Finland has been working on eSocial services since 2004. However, the country does not yet have any legislation on it. KanSa, the extension of this architecture to Finnish social care, is in planning phase. The purpose of the National Project for IT in Social Services (Tikesos), which ran from 2005 to 2011, was to improve IT for the use of social welfare professionals and to make online social welfare services available to clients. Achieving this requires integration of the contents and structures of electronic documents and of document management. Development of information management and IT in social services is being continued by the National Institute for Health and Welfare.

<sup>36</sup> Note, that in contrast to KanTa, SADe supports the development and provision of eServices for the citizens by municipalities on a voluntarily basis.

and social care.<sup>37</sup> The infrastructure seeks to balance local flexibility with a highly structured and centralized information repository that contains lifelong EHRs for all citizens.

At the strategic level, steering is under the responsibility of the Ministry of Social Affairs and Health, and its operational steering and coordination is the responsibility of THL ([The National Institute for Health and Welfare](#)). THL is a R&D institute conducting research, monitoring and evaluation, development, expert opinions, official duties and international cooperation. The social insurance institution KELA is responsible for developing, operating and maintaining the national infrastructure services, KanTa.

### ***Timeline***

**1996:** The Ministry of Social Affairs releases the first national strategy for ICT in the field of social welfare and healthcare.<sup>38</sup> The underlying principle is the development of citizen-centered and seamless service chains, which is considered to require the extensive introduction of new technology, the creation of new types of information system architectures, and better compatibility between information systems. Citizens and patients are envisioned as informed and participative actors in the healthcare delivery process.

**1998:** eHealth strategy is updated,<sup>39</sup> placing emphasis on:

- Adoption of digital patient and client records in all levels of care
- National-wide interoperability between distributed legacy systems
- High level of security and privacy protection

**2000:** Legislation is introduced to build regional information service systems and adapters between existing legacy systems.

**2002:** Decision-in-Principle by the Council of State for the introduction of nationwide EHR by 2007.<sup>40</sup>

A national EHR system development project (2003-2007) was set up as part of the National Health Program.

The Ministry of Social Affairs and Health formed a working group (2004-2007) which produced a definition of national electronic patient records and their implementation strategy and funded a series of regional pilots. The first version of the common content and structure to be used in every EMR system in Finland:

- A clinical consensus on core patient data

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<sup>37</sup> In addition, a new information society program was launched and included an e-welfare program in order to develop ICT for social services – KanSa.

<sup>38</sup> We have not been able to find references to document.

<sup>39</sup> We have not been able to find references to document.

<sup>40</sup> The plans for implementation of national, interoperable EHRs, is one out of eighteen projects in the broader governmental program for securing the future of healthcare.

- A national code server
- Several open standards for interoperability and national guidelines for the safeguarding of data
- Description of basic elements of the architecture needed for the construction of a national data transfer system.

**2006:** Political agreement to develop a national IT architecture - [KanTa](#) - to enable information sharing across the healthcare system, at the point of care. Key services are:

ePrescription and national pharmaceutical database

- eArchive - electronic archive of EMRs
- eView - the citizens' online access to ePrescription and EMR

**2007:** [The Social Insurance Institution of Finland \(Kela\)](#) is made responsible for the implementation of the central infrastructure (eArchive and ePrescription) and the development of the eView (application for citizens' access to the eArchive). Fujitsu services Oy in Finland is the prime contractor and has the overall project responsibility for delivering the KanTa system. Legal foundation for national ICT infrastructure for health is approved by parliament.

**2011:** All the primary care units and hospitals *within* a region are obliged to share database, a feature that was technically available since 2002. Regulation changes from obligatory opt-in, to patient opt-out.

18 out of 21 hospital districts have a regional patient data repository in clinical use, supporting the transmission of eReferrals, eConsultation messages and digitalized images. Five different concepts are identified:

- 1) The *master patient index model* was in use in three hospital districts. Each of them has a centralized reference database of available selected information archived by customer organizations. Authorized users can then use these references as a link to the original data and have access to those selections in the customer organizations. The contents of the original selected data include core narrative texts, digital x-rays and laboratory data.
- 2) The *web distribution model* was used in three hospital districts. Authorized users can have full access to a web-based electronic record of patient data when situated in a secondary care unit. That includes all texts, images and laboratory data that a patient has authorized for the treating physician to see. As this data is distributed online, no special viewer is needed, only a secure connection.
- 3) *Regional sharing of integrated electronic patient data* was used in ten hospital districts. If the patient grants permission, the physician has direct access to the electronic patient record kept by another institution. That includes all the texts, images and laboratory data. In this case both the viewer and the provider use the same proprietary software.
- 4) A *mixed model of patient data sharing* was used in one hospital district where both primary and secondary care is provided by one authority. No extra viewing permission is needed, but because this district has two different electronic patient record software vendors, it uses a special solution with software adapters for its master patient index model.

- 5) *Regional sharing of data from different patient record systems* was in use in one hospital district.

Experiences with the regional health information systems generated a volume of complaints from physicians who found it complicated to extract data out of the system. Pieces of information is scattered throughout the local systems that the patient has been visiting, mainly as unstructured text. While the reference register model enables access across the EHR systems, it still preserves the health information in the proprietary structure specified by each EHR system, health information stored in distributed systems remains semantically incompatible. Healthcare personnel use a lot of time to search documents and the search function is not well-developed. As a result there is a low level of usage (only 5 % of physicians report using shared data).<sup>41</sup>

For those systems that did reach a high level of user satisfaction, success factors were identified as ease of information retrieval and comprehensiveness of data, as well as those functionalities that doctors need in their everyday work.

**2013:** The Finnish government initiates an international peer review process and gathers feedback in a [report](#) on future direction for Finnish eHealth.

**2014:** Mandatory by law for all public service providers to provide data to the national eArchive (private providers will have to do so by 2015, given that they maintain electronic archives).

The Ministry launches a new strategy for information management in health and social care. We have agreed with the Ministry that they will provide an English translation of the strategy this Spring.

**2015:** Finnish Government unable to reach an agreement on the SOTE-reform.

An update of the national eHealth strategy is released. [Information as support for welfare and the reformed services: Exploiting social and health information - strategy towards 2020](#). The strategy shifts focus from gathering and transferring data to using information for individual welfare and capability to cope with different life situations. The system should support patient work, governance and research in the healthcare sector. This implies that the information in different databases must be analyzed, interpreted and reshaped into knowledge. For that purpose, information must be transparent, commensurable and comparable, as well as relevant and easily accessible.

The main objective of the eHealth strategy is to support the reform of health and social care and to increase citizen involvement in caring for their own welfare through improved information handling and more eServices. This implies that the citizen should be activated to self-service, and use eServices for simpler procedures, in order to increase face-face capacity for those patients who need it the most.

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<sup>41</sup> The reference here is [the regular national monitor on eHealth in Finland, Checkpoint](#).

A main mechanism for realizing the objective is to strengthen national and regional governance in order to increase capacity to realize the strategy. The health and social care services should produce nationally unified information and computer systems should be harmonized at a regional level, as well as nationally interoperable. Relevant financing models are to be developed. New services are to be developed and procured through collaboration by means of the national service architecture and principles of modularity.

A collaboration model is to be established in order to integrate social care and healthcare, and facilitate better coordination of the municipalities' cooperation on eHealth, and their strategic collaboration with the Ministry of health and Social Affairs. Decision making procedures are to be part of this model.

Given that the SOTE-reform has not yet been concretized, the strategy for eHealth is not specific on how the governance model is to be constructed.

The strategy includes the following key efforts:

- Development of a national citizen platform for management of personal health information.
- Development of coherent, multidisciplinary plans for patients in frequent contact with the healthcare system.
- Engage healthcare professional in procurement, and enterprise development processes
- Strengthen eHealth in professional education and training
- Standard, structured information for decision making on individual patients developed and made accessible for healthcare providers across the sector.
- Continuous development of legal framework in order to adapt to increased information sharing
- Include social service database in KanTa
- Include PACS and dental care in KanTa
- Awaiting the decision on the SOTE-reform, action plans, placing responsibility for efforts and their financing, are to be developed for the eHealth strategy, fitting the strategy according to the content of the reform.

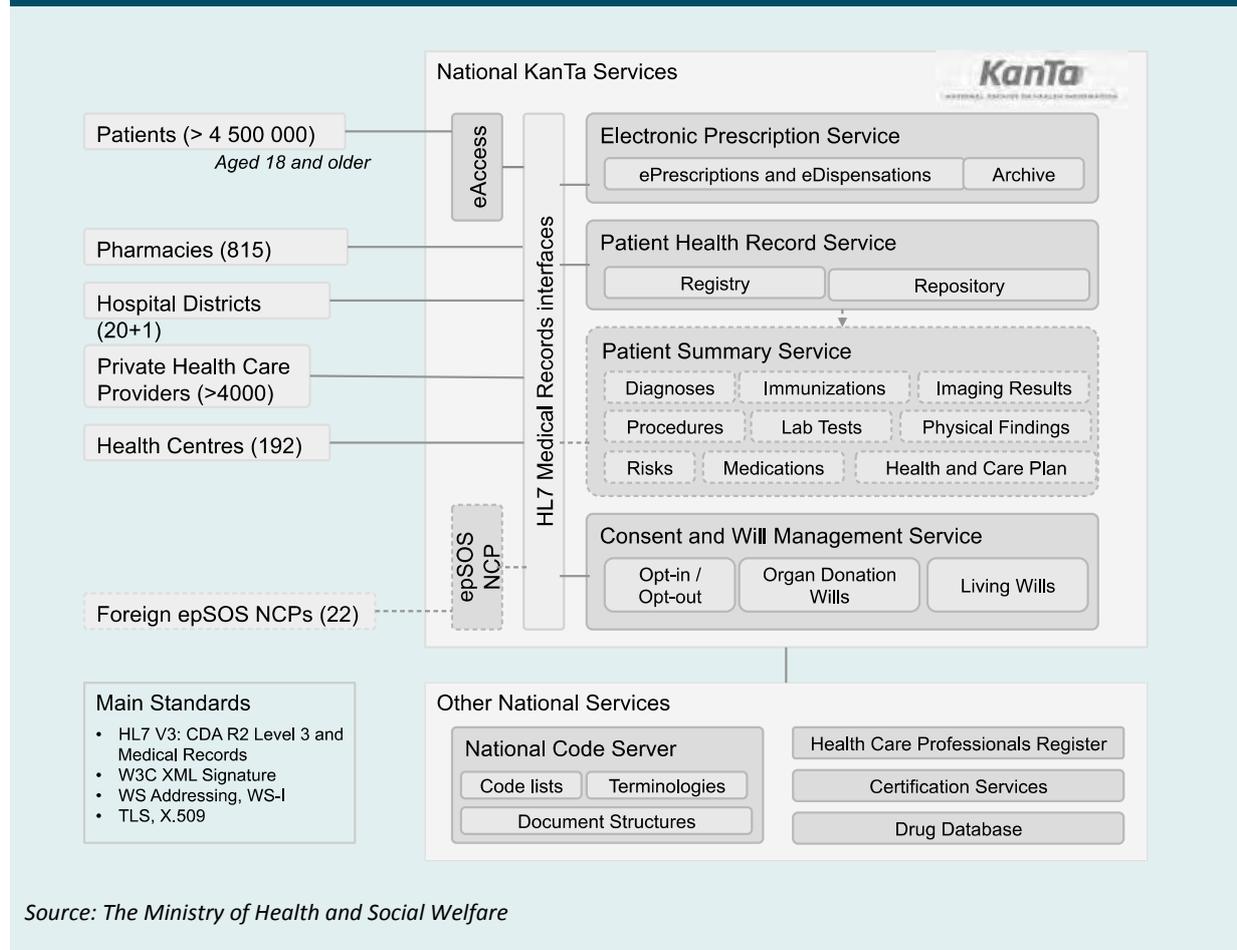
#### **4.6 The Current Finish eHealth System**

The Finnish information model for eHealth builds on the Service Oriented Architecture (SOA) and on a highly structured implementation of CDA R2 documents. Semantic interoperability for nationwide health information is achieved through a centralized information model and storage to gather in the centralized archive. The KanTa architecture defines the centralized information model, software design principles, and technical baseline for Finnish eHealth.<sup>42</sup>

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<sup>42</sup> <https://www.fujitsu.com/global/Images/paper15.pdf>

Figure 9. Illustration of the national eHealth system – KanTa



#### 4.6.1 Infrastructure

The main users of KanTa are legacy systems and patients. Information between legacy systems and common services are transferred in the form of documents. Citizens and patient are connected to the eArchive via web services which acts as an integration machine. All local EMR systems connected to the national platform should be certified for functionality, interoperability and security. Legacy systems are required to adapt to the following services before using national services:

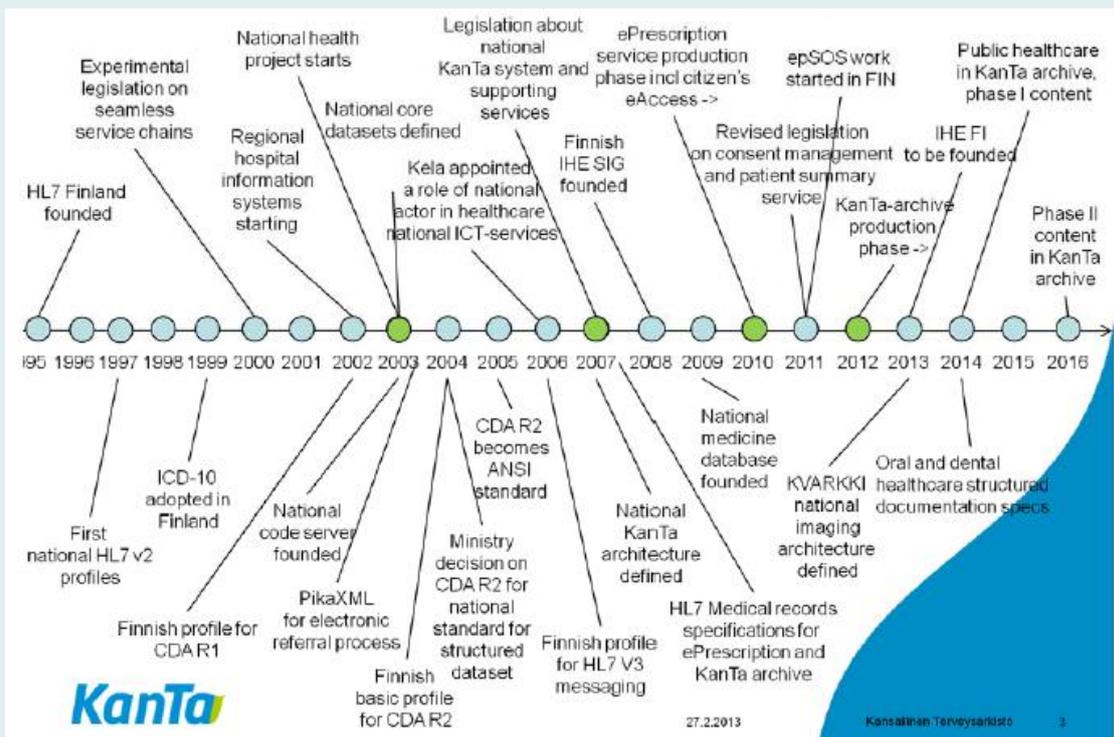
- A data entering application to support common headings, terms, classifications and the core data set
- Creation of consent document and relationship credentials
- Capturing data from the local database
- Creation of HL7CDA and DICOM messages
- Creation, preservation and access requests which are sent to the eArchive
- Viewing received EHR-messages
- Generating audit logs

Due to a well-developed public communications network in Finland, investing in creating a closed network dedicated to healthcare was not deemed necessary. The demands of healthcare telecommunication have been served through the use of commercial high-speed public data networks and virtual private network (VPN) tunnels over the public network.

The KanTa services are based on web service technology, and selected services are exposed to integrated systems through KanTa's messaging interface. Each web service is defined using the WSDL and the related XLM Schema Definition (XSD) as specified in the Web Services Interoperability Organization's Basic Profile 1.1 standard. Thus, WSDL describes the Web Services and how to access them from the technical viewpoint, and XSD specifies the legal building blocks of the messages including the CDA R2-based structure of the healthcare information that can be stored in KanTa.

#### 4.6.2 Infostructure

Figure 10. The planning and implementation of eHealth standards in Finland since 1995



Source: The Ministry of Health and Social Welfare

Finland has a long tradition in defining structured health records. Back in the 1980s, the association of local and regional authorities designed a set of paper health records for both primary care and specialized care, and they became widely used. In the various departments of each hospital, the documentation sheets had the same structure, e.g. for laboratory and x-ray results. In the healthcare centers, GP records were kept for life.

KanTA provides a unified messaging interface based on HL7 v3 for integrating the systems and the ISO 17799 standard for Information Security Management (based on the BS7799). All messages have a header with harmonized meta-data and a structured body section supporting the previously mentioned EHR structure. For security, all documents are signed electronically and transferred in a Simple Object Access Protocol (SOAP) envelope.

In KanTa documents are highly structured and narrative blocks are used only to describe small elements where free text is needed. When KanTA receives information from the EHR system, the document inside the received message is initially validated first and stored only if the data is valid. As a result, the meaning and context of information stored in KanTa is unified (HL7 CDA), so it is

semantically interoperable, which enables information to be exploited for various needs. Using that interface, EHR systems, pharmacy systems, and citizens using the health information portal can read and manage health information stored in KanTa depending on their access rights. In the future, the plan is for all patient data (including x-rays, i.e. imaging data) will be stepwise subject to specifications that will enable central storage.

The deployment of the eHealth structure is based upon nationally approved terms, classifications and codes, which are updated by the national code server. [The National Code Server](#) is a key instrument to cross-link and harmonize codes and terminologies that are needed for a reusable digital documentation of health related problems and conditions. Since 2011, THL is responsible for the code server.<sup>43</sup>

#### 4.6.3 Privacy, Information Security and Access Control

The national guidelines for the safeguarding of data contain rules of procedure for informed consent, secure archiving, e-signature, identification of patients, documents, professionals and organizations by ISO/OID-standard, and a PKI architecture.

The precondition for EHR disclosure is the presence of doctor-patient relationship, patient's consent or explicit legislation. It is the responsibility of legacy systems to create the relationship credential and consent document. Healthcare persons and entities are identified and authorized using the common PKI-service.

The security infrastructure of KanTa service provides strong eID for all users.<sup>44</sup> The users log in either by using Internet banking IDs or national eID cards. An extension supports the use of digital certificates for health professionals. The services are hosted and maintained by Kela.

The access to personal health data is also used to manage consent in the KanTa system. When consent is given it is usually unlimited. However, it may be limited to certain types of data (such as the period and the provider). Health professionals can prevent or postpone the display of data to the patient, e.g. in terms of life-threatening diseases. Patients can also monitor access to their data through an audit facility.

All messages are logged in the centralized logging service, which provides detailed information about creating, changing and reading events in the KanTa system.

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<sup>43</sup> For more information on the development and management of the national code server, please see: [https://www.julkari.fi/bitstream/handle/10024/110626/URN\\_ISBN\\_978-952-302-042-9.pdf?sequence=1](https://www.julkari.fi/bitstream/handle/10024/110626/URN_ISBN_978-952-302-042-9.pdf?sequence=1)

<sup>44</sup> The Finnish Unique Identifier (FINUID) is issued by the Population Register Centre to citizens born in or outside Finland on the basis of a birth certificate. FINUID is mapped to the Social Security Identity Number which functions as a unique identifier for Finnish citizens and permanent residents to eGovernment services. When providing citizens with a personal identity code, the Population Register Centre creates also an electronic identity for them (FINEID). Cards for identification of professionals are provided by the Population Register Centre (VRK).

#### 4.6.4 Shared eHealth Components and Services

**ePrescription:** contains all data on medication prescribed by physicians and delivered by pharmacies in a ePrescription data center. Data are accessible by physicians, dentists, pharmacists and students, and also by healthcare professionals assigned to handling requests for renewing prescriptions at healthcare service units who have been issued with a professional card.

**eArchive:** is a national, secure and consistent electronic archive of patient health records. Using the eArchive system, healthcare professionals treating a patient anywhere in the country can have access to all previous information about the patient, with the patient's consent.

**eView:** gives citizens have access to their personal health information online. They can view and print out a summary of their prescription information and patient records. The patient records only show information approved by a medical professional. Access to one's personal information requires authentication with an online banking code or eID.

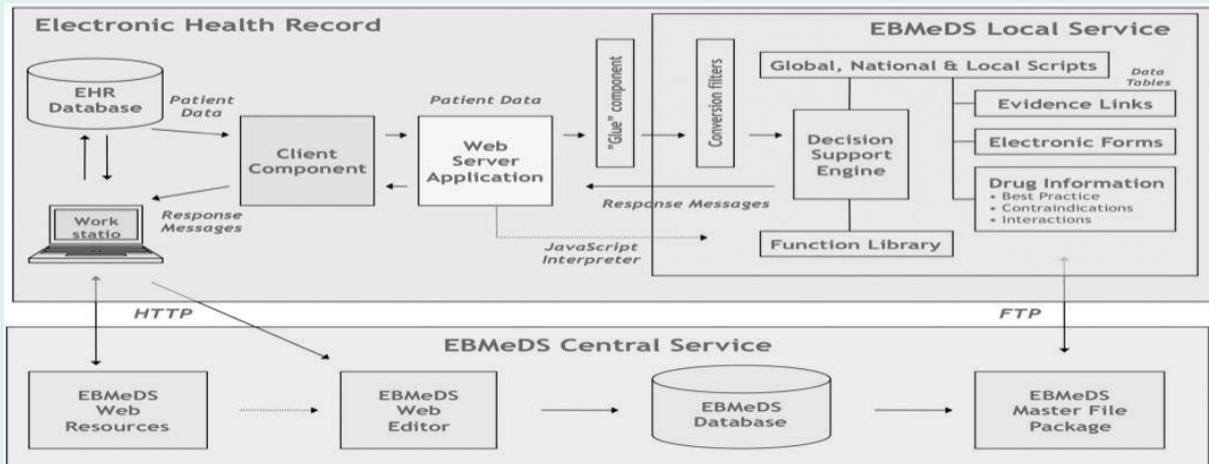
[the Finnish Medical Society - Duodecim](#) maintains and updates the standalone online database - [Terveysportti](#) (In Finnish) which serves as a portal for databases dedicated to physicians' database and for nurses' database. In addition, Terveysportti is a portal for several databases concerning good clinical practice, evidence-based medicine guidelines, the Cochrane library, guide for interpreting electrocardiograms, medicines, drug interactions, international classification of medicines, libraries of common chronic diseases, etc.

**EBMDeS (evidence-based medicine decision support system)** covering a wide variety of clinical topics based on structured core data from the EPR system, have been developed by Duodecim.<sup>45</sup> EBMDeS utilizes data from various EMR systems, which are compatible with the national EHR standards. With the help of an expert script language, EBMDeS brings context-sensitive information from a central server directly to the EMR of the patient. Databases for the decision support system have been designed for physicians, nurses and other healthcare professionals in primary and specialized healthcare.

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<sup>45</sup> Integrated decision support systems are available in all hospital districts and healthcare centers and most of the private service providers. The official Finnish eHealth monitor, [Checkpoint 2011](#) shows that the status of integration differed. In 2011, standalone online database on the desktop was in use in 76 % of the hospital districts, in 88 % of the primary healthcare centers and in 87% of the private providers. A database with access by navigating from EPR was in use in 38 % of the hospital districts and in two thirds of the healthcare centers and one third of the private providers. Those displaying a selected item on the desktop (reminders and drug interaction systems) were the most common solutions. Automatic displayers of selected items were in use in 20 % of the hospital districts and in three fourths of the healthcare centers and one tenth of private providers. Systems for automatic integration of EPR and a medical knowledge database were in use in 24 % of the hospital districts and in around one third of the healthcare centers and two of the private providers. The most common of these was the drug interactions system.

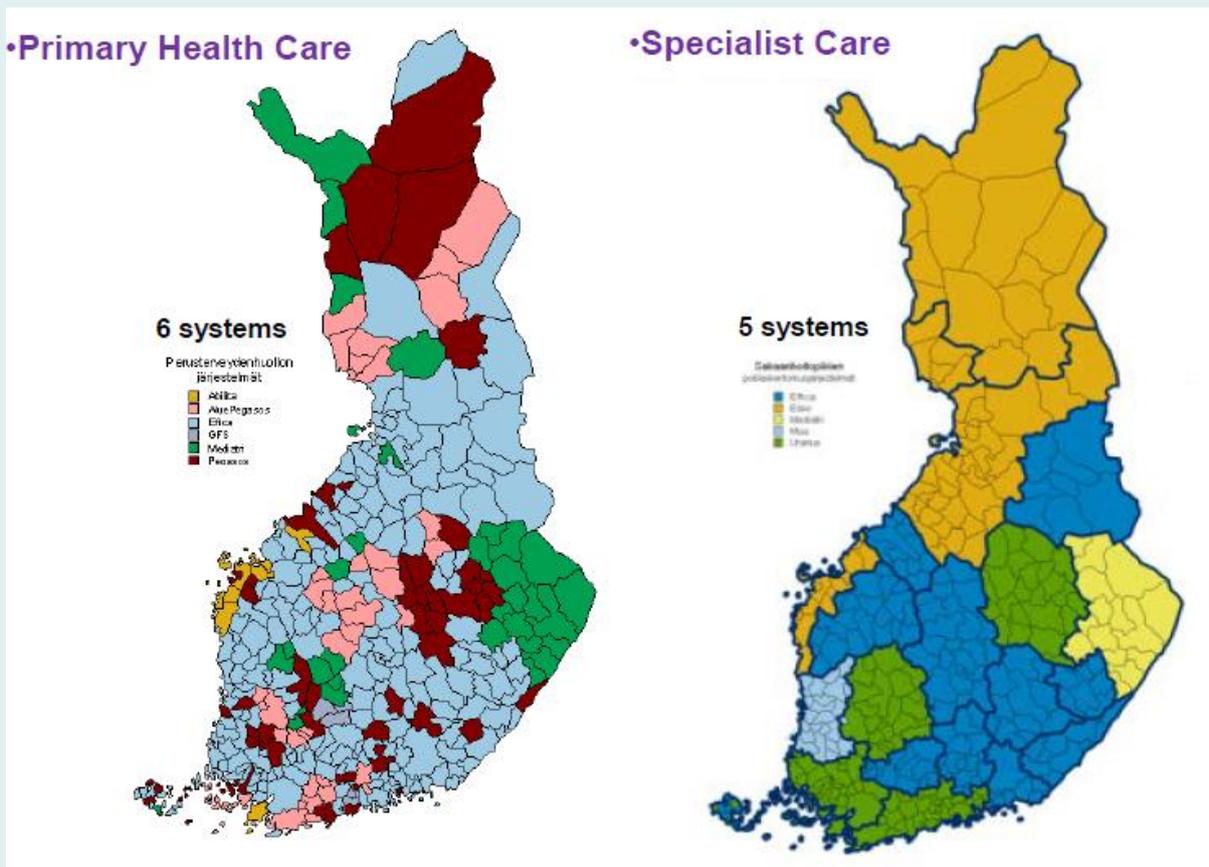
Figure 11. Scheme of the functional architecture of the EBMeDS, Duodecim



Source: Duodecim

#### 4.6.5 EHR landscape

Figure 12. Illustration of the EHR landscape, full EHR deployment, many different system vendors



Source: THL

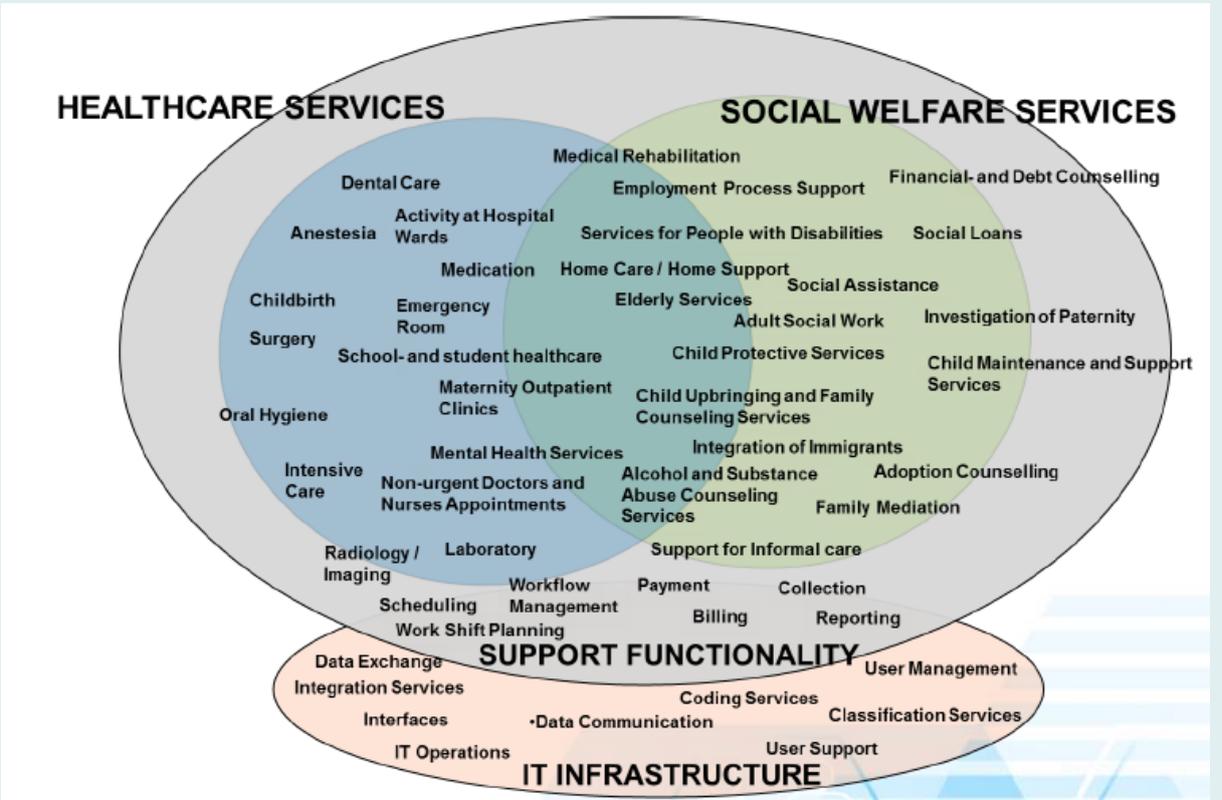
A total of seven different electronic health record systems are used; five in public primary care and four in public hospital-based specialized medical care (while two systems are used in both settings).

The decision making processes surrounding EHR systems is described as very fragmented, with too many organizations with conflicting interests. Small organizations do not have sufficient procurement power and lack *know-how*. Health IT market is too centralized and controlled by a few vendors. While interoperability specifications exist, there is a need to lower barrier of interoperability specifications to enable new innovative SMEs to enter the market.

Most probably the operational EHR and PACS archives will be consolidated within the new SOTE-regions with a connection to the KanTa.

**A regional example of EHR development**

**Figure 13. APOTTI Program System landscape**



Source: APOTTI

Established in 2011, the [“Apotti” Program](#) is multi-organizational program directed at improving the functionality, effectiveness and service quality for both social welfare and healthcare services in Finland’s capital region. The program will impact public services for a population of 1,5 million citizens, 30 hospitals, 40 health stations and 50 social welfare offices.

Major goals of the program are significant overhaul of the IT-systems used to manage records, clinical data and harmonizing operational practices towards a data-driven and evidence-based model of providing services.

Part of the program is the procurement of an EHR system from the American IT vendor Epic which is to be implemented by 2019.

The aims are:

- Citizens' services such as electronic alternatives to GP or hospitals visits, eBooking, and possibility for patient to enter information whether forms, test results or observations.
- A sharde, user-friendly tool for professionals in the coordination of health and care services, offering support for decision making and agreed-upon service protocols.
- Support governments by integrating methods for different areas of health and social care, thus making them easier to manage, as there are fewer areas that need developments that overlap. The system should provide information on services and their quality to support improvement work.

According to a cost-benefit-analysis conducted by the APOTTI program, the total cost over 10 years for the new client and patient data system would be 335–430 million euros. Costs include the procurement price, implementation, migration and annual operational costs. The costs of the procurement are divided among the members of the pool, but there has not been a decision on how to split the costs yet.

#### 4.6.6 Digital Services for Citizens

In 2009 the Finnish government launched an action program for eServices and eDemocracy (SADe) to provide digital means to foster citizens' participation and the development of eServices in social welfare and healthcare. The long-term vision is to help citizens to take responsibility for their own well-being and prevent various health problems.

For the healthcare sector, the aim is to develop national eServices for citizens that include generic health information and decision support for citizens, electronic health checks and risk tests with decision support for citizens, indexing for the national-level service and provider database ("yellow pages") and feedback services. National system and information requirements will be drawn up for eBooking and eMessaging services.

In order to coordinate and enable knowledge exchange between projects developing similar eServices, all public funding of eHealth projects, regardless of the source, is coordinated by the Health and Welfare services development program (Kaste) led by the Ministry of Social Affairs and Health.

#### 4.6.7 Secondary Use of Data

THL is responsible for health statistics. It organizes the registration of the data, analyses it, publishes the data publicly, and interacts with the various responsible international organizations, such as the OECD and WHO.

Finland has many different national registers, the first established is for cancer. Two registers stand out as they can support the monitoring of changes to healthcare provision associated with the further deployment of the KanTa national health IT infrastructure:

HILMO hospital discharge register. The mandatory reporting comprises specialist hospitals and local (GP-run) hospitals in the private and public sectors and all types of care. It was extended to institutional care in social services (especially elderly care) from 1998 onwards.

AvoHILMO register of primary care visits. Established in 2011, allows planning, monitoring and comparing services at a local level for many purposes such as verifying the guaranteed access to treatment and monitoring the level of health examinations. It also supports the production of epidemiological data (e.g. on injuries and epidemics) for national/international statistics. Taking into account the method of generating registry data through automatic extraction from health IT systems that are being used for routine healthcare, AvoHILMO may be seen as a prototype for future register operation based on the eArchive.

In the new eHealth strategy (2015) secondary use of health data is a prioritized area. The ambition is to have access in real time to information that supports the management of service provision and societal decision making.

Information that has been gathered and produced through tax based funding should be made available as open data. Patient specific data from the healthcare services, information about service availability, quality and effect, information entered by the citizens themselves as well as information from other sectors should be made available and exploited in a secure way in different systems in order to improve service production, society and citizens. A legal revision is needed to ensure that data stores in national and regional databases can be used for secondary purposes. This will be developed, also taking into consideration developments within EU law.

National and regional targets for gathering and use of enterprise information, and a national plan is to be developed which reflects the ambitions in the reformed healthcare structure and its enterprise demands into relevant indicators according to an information architecture. Statistical and indicator services at a national level shall be developed in order to work in accordance with the national databases. The principal is that information should be registered only once, and for the information to be usable for other purposes than the original intent. The plan is to establish a national infrastructure for all kinds of purposes for use of secondary data – with shared services for research, monitoring, etc.

## 5 Estonia

### 5.1 Demographic Data and Political Tradition

Population (2013)	1 324 612
Area (km <sup>2</sup> )	45 227
Political tradition	Parliamentary republic
Administrative levels	State, county, municipality

### 5.2 Key Figures for the Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	76.2
<b>Expenditure on health</b>	
In percent of GDP	5.9
Per capita (USD purchasing power parity)	1 303
Public financing (% of total expenditure)	80.2
Private financing (% of total expenditure)	19.8
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	3.3
Practicing nurses (per 1000 population)	6.2
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	6.3
Hospital discharges (per 1000 population)	174
Total hospital beds (per 1000 population)	5.31
Average length of stay, all causes (days)	7.7
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	92.9
Out-of-pocket medical spending (% of household consumption)	2

Source: OECD 2013

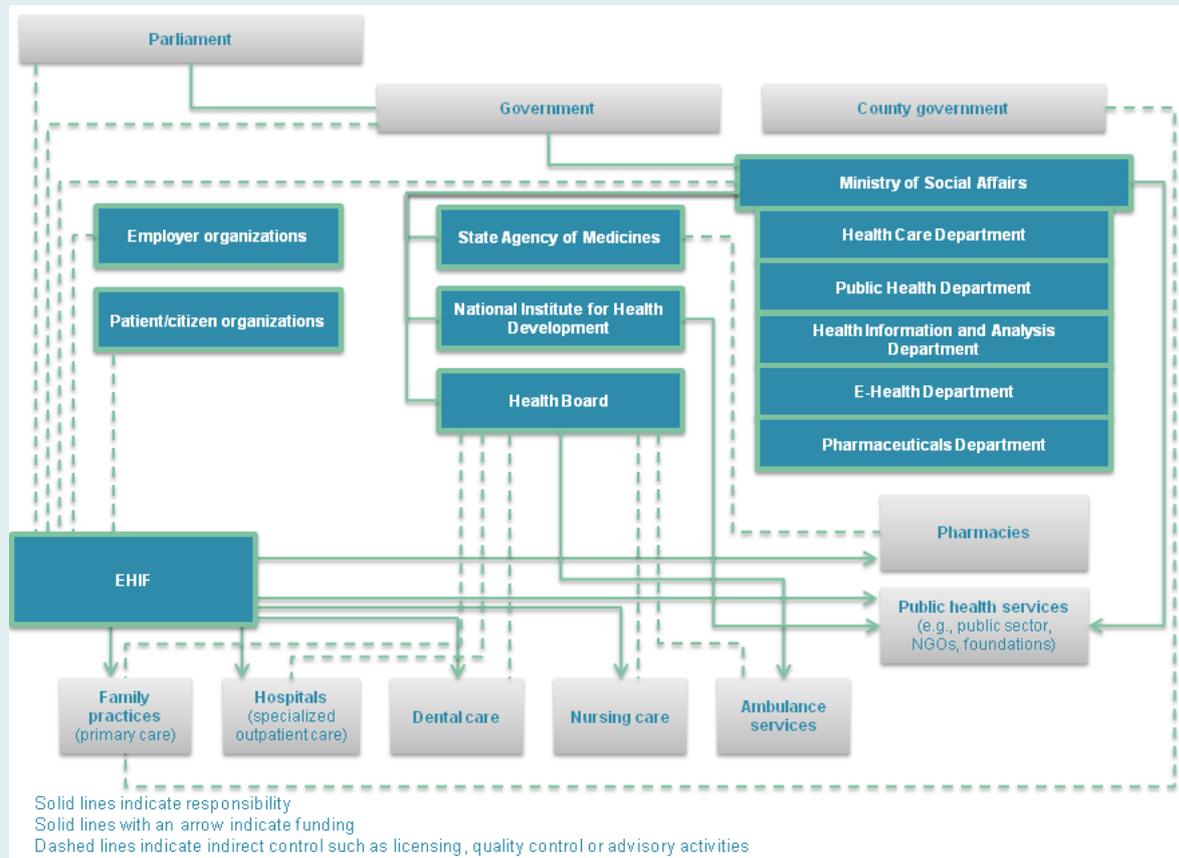
### 5.3 Gathering Information on the Estonian Case

The empirical material for this chapter is gathered through desktop research, May-June 2013 and January-March 2015. Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Estonian healthcare system, eHealth strategy, key actors and initiatives.

In this chapter we will use the empirical material to describe the past, present and future of the Estonian eHealth system. Obviously, the description is not exhaustive. The report reflects the knowledge needs of the Norwegian One patient – One record program.

## 5.4 Financing, Governing and Organizing Healthcare in Estonia

Figure 14. Estonian Healthcare System



Source: Koppel A, Kahur K, Habicht J and van Ginneken E. 2011

Gaining independence from Soviet Union in 1991, Estonia engaged in fundamental reform work to establish the foundation for a national healthcare system. Today, the Estonian health system provides universal access to health services, based on compulsory, solidarity-based insurance in the form of an earmarked social payroll tax (13 % paid by the employer), which amounts to about two-thirds of total healthcare expenditure. Patients can themselves choose provider freely.

The Estonian Health Act defines four types of healthcare:

- Primary care provided by family doctors
- Emergency medical care
- Specialized (secondary and tertiary) medical care
- Nursing care

Stewardship and supervision as well as health policy development are the duties of the Ministry of Social Affairs and its agencies. The Ministry of Social Affairs and its agencies are responsible for the financing and management of public health and ambulance services financed by the state budget.

Most hospitals are public, owned by the state, local governments or public legal bodies. In many instances, hospitals have multiple owners, or the state and municipalities jointly own one hospital.<sup>46</sup> All hospitals are required to operate under private law as joint-stock companies or foundations. Most ambulatory providers are privately owned.

Local governments do not have any legal responsibility for funding or organizing healthcare. However, as owners of hospitals, local governments play a role in healthcare through their position in hospital boards.

All family doctors are private entrepreneurs or salaried employees of private companies owned by family doctor(s) or local municipalities, practicing on the basis of a practice list (average 1750). Family physicians have a partial gatekeeping function.

Palliative care and long-term care are delivered as part of nursing care (which is currently in shortage in Estonia). Pharmaceuticals are distributed to the public through privately owned pharmacies. Since April 2013, pharmacies can also distribute pharmaceuticals through the internet.

#### **Demographic trends and ongoing healthcare policy debates and reform**

The provision of healthcare has been almost completely decentralized since the reforms that took place in the early 1990s. Planning of primary care and some specialist care was devolved to the municipalities. However, some functions were decentralized to levels that were unable to ensure efficient performance. Most municipalities were too small and lacked sufficient financial resources to fulfil their new functions. Towards the end of the 1990s began a period of (re)centralization in which the state regained control of overall planning and administration. In recent years, only incremental changes have been implemented.

The health insurance system covers about 95 % of the population. Contributions are related to employment, but the share of non-contributing individuals (e.g. children and pensioners) represents almost half of the insured. In the longer term, this is a threat to the financial sustainability of the health system, as the narrow revenue base is mostly related to wages and the population is ageing. As a result, public expenditure on healthcare is relatively high and the Government faces continuous pressure to decrease it. The challenge proliferated as the economic crisis struck Europe in 2008. At the same time, patients expect prompt access to medical services without any deterioration in quality of service. In the past, the strategic planning capacity of Estonian public authorities and

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<sup>46</sup> For hospitals a diagnosis-related group (DRG) system has been implemented since 2004, complementing the fee-for-service payments and those related to bed-days. With regard to primary care, age-adjusted capitation, fee-for-service payments for selected areas and basic allowances have been complemented by a quality bonus scheme (QBS), implemented in 2006, which aims to foster disease prevention and management of selected chronic conditions.

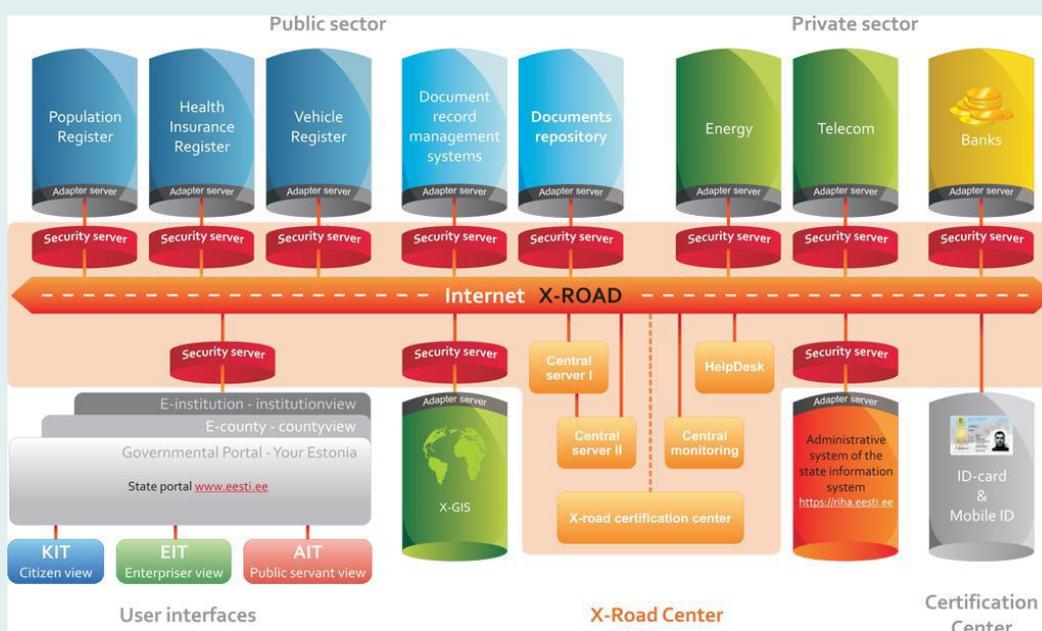
political institutions has been hindered by the absence of a reliable and integrated means of collecting and collating medical data. Planning of new medical establishments, national vaccination programs or the procurement of medical equipment all suffered as a result.

By improving efficiency and performance, eHealth is seen as key for the development of a more sustainable healthcare system. Moreover, the Estonian eHealth system is to be understood in the context of an overall national initiative to use eSolutions to develop innovative electronic solutions to provide improved access to public services.

As the Estonian Parliament (Riigikogu) adopted the [Estonian Information Society Strategy 2013](#) in 1998, the country set out to build a digital public welfare system. With financing from the EU structural fund, an ambitious list of aims was formulated<sup>47</sup>:

- All public services are digitally available
- Public infrastructure is service oriented (x road)
- Digital authorisation of users, based on the ID card, is the best available in the world
- Data is stored where it is collected and exchange of the data is available for those who need it

Figure 15. The national infrastructure X-road



Source: The eHealth Foundation

<sup>47</sup> Between 2004–2006, Estonia was allocated 12.5 billion NOK from the EU Structural Fund, of which 130 million NOK were used to support the development of the information society. In the period 2007–2013, the development of the Estonian information society was supported with 62.6 million euros in targeted funds.

Before the EHR project, no integration existed between different systems, or a systematic digital medical data exchange in the medical community. What resulted was the national infrastructure called [X-Road](#), which was launched in 2001 based on two key components; *eID for all citizens* and a *flexible service platform* that supports growth of services. X-road is a technical and organizational milieu that provides a foundation of trusted identity, policy compliance and secure and transparent information transactions. As a technical concept, X-Road does not imply translation of databases into a larger management system. Instead, X- road uses an integrated set of user interfaces in order to organize communication with different databases. The concept enables dialogue between patient and a multitude of databases as well as the collaboration between application programs and databases. Using their eID, the user can access existing documents and add new ones. A number of components are “plugged” into the X-Road, and new ones can be added by providing adapters into the X-Road Platform.

The [Estonian Information Systems Authority \(RIA\)](#) a sub agency of the Ministry of Economic Affairs coordinates the development and management of the national Information systems, organizes activities and acts as advisor in issues related to information security.

### ***5.5 Estonian eHealth: Past, Present and Future***

[The Ministry of Labour and Health](#) is responsible for governance of the health information system in Estonia. This responsibility is shared between the Department of Health Information and Analysis and the Department of eHealth. The former is responsible for developing the overall infrastructure of the health information system and health indicators, and for providing analytical input in setting policy. The latter focuses on development of eHealth services such as ePrescription and EHR systems. The health registries are a joint responsibility of these two departments.

eHealth was a fundamental component of the X-road project from the beginning. The Estonian Health Information System (EHNIS) was launched in 2008, building on the national infrastructure. At the heart of EHNIS is the nationwide EHR system collecting and storing the health information for virtually all the country’s citizens throughout the life cycle. The aim is to improve the continuity and integration of care by making it possible to exchange relevant health information across the healthcare system.

Estonia has received much international acclaim for its rapid and relatively inexpensive development of a national eHealth system. Total budget €1,594,941 (ERDF contribution €1,196,206 national budget €398,735). Today, Estonian citizens can go online to order prescriptions, book appointments with their doctors, read their health record, view test results and pictures. This has led to a significant decrease in GP visits. In the following, we take a closer look at the development of Estonian eHealth.

## **Timeline**

**2000:** Plans for development of a national eHealth system starts.<sup>48</sup> During the first years of the NHIS project, a series of feasibility studies were undertaken which formed the basis for the Estonian Digital Health Record Vision document. The objective was to develop a national database for the management of a multitude of medical documents in a digital format and facilitate the exchange of highly diverse health information. The Ministry of Social Affairs also executed a Regulation setting the minimum information for health records in Estonia.

**2005:** Four fundamental elements of ENHIS are singled out and funding approached by the Ministry of Economic affairs:

1. Electronic Health Record (1.6 million €)
2. Digital Registration (0.2 million €)
3. Digital Images (0.2 million €)
4. ePrescription (0.24 million €)

In order to effectively manage the ENHIS project, the Ministry of Social Affairs initiated the development of a separate administrative body under the regulatory supervision of the Ministry of Social Affairs, [the Estonian eHealth Foundation](#) (e-tervis). The foundation is set up as a broad collaborative effort between Central government, professional organizations, and enterprise unions.<sup>49</sup> Its main responsibility is to develop, promote and manage the national e-health system and its components,<sup>50</sup> develop and manage standardization, and to act as a national competence center for eHealth.

**2006:** ID-cards rolled out. The card, which is valid for 10 years, is used for identification but also as a travel document within the EU. ID cards are used for visual identification of persons, to access different Services, for electronic identification and for digital signatures and can be verified against

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<sup>48</sup> The idea for developing a National Health Information System was first introduced by the Estonian Health Project 2015, which was initially a preparation for the follow-up loan to the first World Bank financed health system improvement project (1995-2000). The main concept of the current strategy dates back to 2000, while general features were prepared by 2002, when the Estonian Health Project 2015 was terminated and the Health Division of the Ministry of Social Affairs took fully over the responsibilities for the entire process. In 2003, the Department of Health Information and Analysis was established for the practical development of the strategy. Another document, which is indirectly concerned with the renewal of the health system in terms of IT deployment, is the "Estonian Hospital Development Plan 2015" (HNDP). It was initiated in 2000 (updated 2003) to re-organize the hospital network with the underlying idea of concentrating high-technology specialist care into major centers to raise the efficiency and quality of the services. The Plan determined the list of regional, central, general, local and specialty hospitals based on the access criteria to ensure sufficient population pools with necessary catchment.

<sup>49</sup> Partners include the Ministry of Social affairs, Estonian Hospitals Association, Estonian Health Insurance Fund, Estonian Society of Family Doctors, Estonian Health tech Cluster, Estonian Information System's Authority, Data Protection Inspectorate, Health Board, and the National Institute for Health Development.

<sup>50</sup> The Foundation participates in procurements related to healthcare system's know-how, and ensures that they are interfaced with the EHR system. The Foundation will participate in creating the basic procurement functions as well as in assessing the procurement outcome. The Foundation has compiled the general recommended requirements for the tender documentation, to enable interoperability with existing and new systems.

the Population Registry. Because of the concept of the Estonian ID-card, according to which the smart card itself does not contain any other information than that necessary for the identification of a person, there is no longer need for a special health insurance card. A person identifies with an ID-card, while insurance information is maintained in the respective database.

**2007:** Following an extensive revision of the legal framework, it becomes mandatory for healthcare providers to forward an agreed set of medical information on standardized form to the Estonian National Health Information System (ENHIS). The legal revision also included content standards, storage procedures and Prerequisites for privacy and information security.

**2008:** ENHIS is launched and will undergo gradual development up until completion in 2013. An open procedure for procurement was employed by the Foundation for the procurement of Health Information Exchange (HIE) infrastructure.<sup>51</sup> Invitations were sent to suppliers who could comply with the Foundation's standards for hardware and software (see below). From 2008 to 2010, the Foundation delivered the basic infrastructure. From 2011, infrastructure services have been purchased from a private service provider.

The Estonian Ministry of Social Affairs started training healthcare workers to be able to use the newly developed and implemented systems. From April to August 2008 about 9000 potential users (healthcare workers, pharmacists, etc) have to pass that training countrywide.

**2009:** [Patient portal](#) (In Estonian) is launched, providing citizens with online access to their EHR.

**2014:** The National Audit Office releases a report, criticizing the national eHealth program for failing to deliver on its objectives. In particular, the report points to very low usage rates for the ENHIS and poor quality and major gaps in the data actually being reported to the system. The Government is criticized for not being sufficiently involved in ongoing developments, leaving too much responsibility with the eHealth foundation.

Later that year the Estonian government set up an eHealth task force to operate within the Government office, with the goal to develop a strategic development plan for eHealth until 2020, along with a detailed implementation plan.

**2015:** New national [eHealth strategy 2020](#)<sup>52</sup> launched. Main aims as follows:

1. **User-centered and science-based precision services** - Full personalized data available to compute individual or group risk profile, and based on that provision of decision-support, guidance and targeted services / interventions. Full pre-analyzed data profile about an individual available universally.

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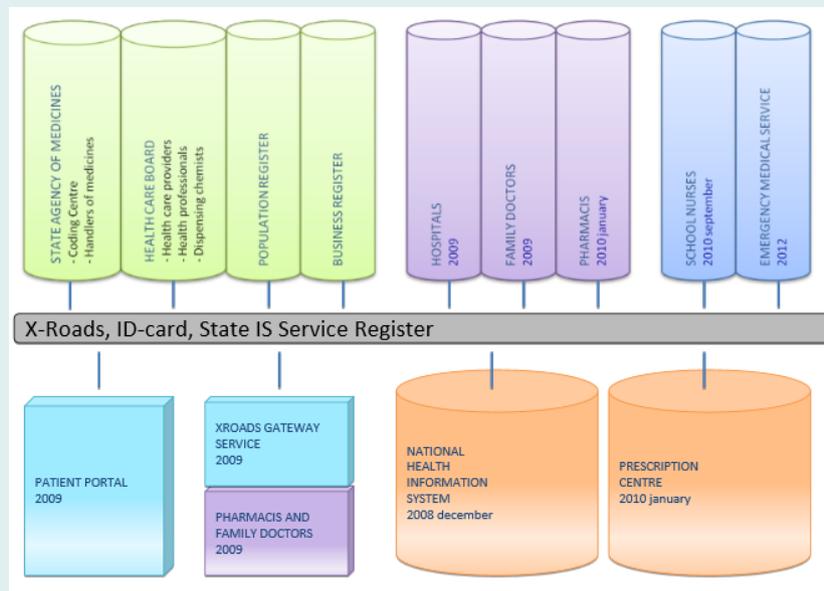
<sup>51</sup> [http://www.pro-ehealth.eu/casestudies/ProeHealth\\_Case\\_Report\\_Estonia\\_EHR.pdf](http://www.pro-ehealth.eu/casestudies/ProeHealth_Case_Report_Estonia_EHR.pdf)

<sup>52</sup> We have not been able to maintain an English version of the strategy, and thus link up a presentation by the Task Force.

2. **Holistic case management and integrated service network** - Every provider has (past and future) overview of and carries the responsibility for outcome across the whole service pathway until full conclusion of the episode.
3. **Improved service performance and quality** - Planning and decision at all levels (provider to state) is supported by performance/quality measurement of and prediction about final and intermediary outcomes.
4. **Optimized service access and professional time use via telesolutions** - Teleservices (-care, -health, -medicine) and m-services are natural part of health and social services, in order to reduce unnecessary work time, user time and overall cost to the society.

## 5.6 Current National Estonian eHealth System

Figure 16. National eHealth Architecture in Estonia



Source: The eHealth Foundation

Architecturally speaking, the EHR is a centralized information system, a Health Information Exchange (HIE) platform. The platform utilizes already existing state infrastructure such as electronic ID cards and X-Road security and communications. In its essence, ENHIS is an integration environment that will be developed without modifying the existing local information systems (the systems will merely need minor adjustment for enabling them to support central message-based data exchange).

Important keywords of the digital information system architecture are:

- Service oriented architecture (SOA)
- Standard communication method with external information systems via common message centre
- Autonomous services
- Scalability and fault-free – backed up in two locations
- Easy to add new services

Partners who interface with ENHIS and internal services use a unified message module, an agent centre. The agent centre offers the partners in the information system a central security solution

including the administration of rights and users and authentication and authorization of users and logging. The centre is offering integration with external information systems, and message administration and message-based integration with other information system modules.

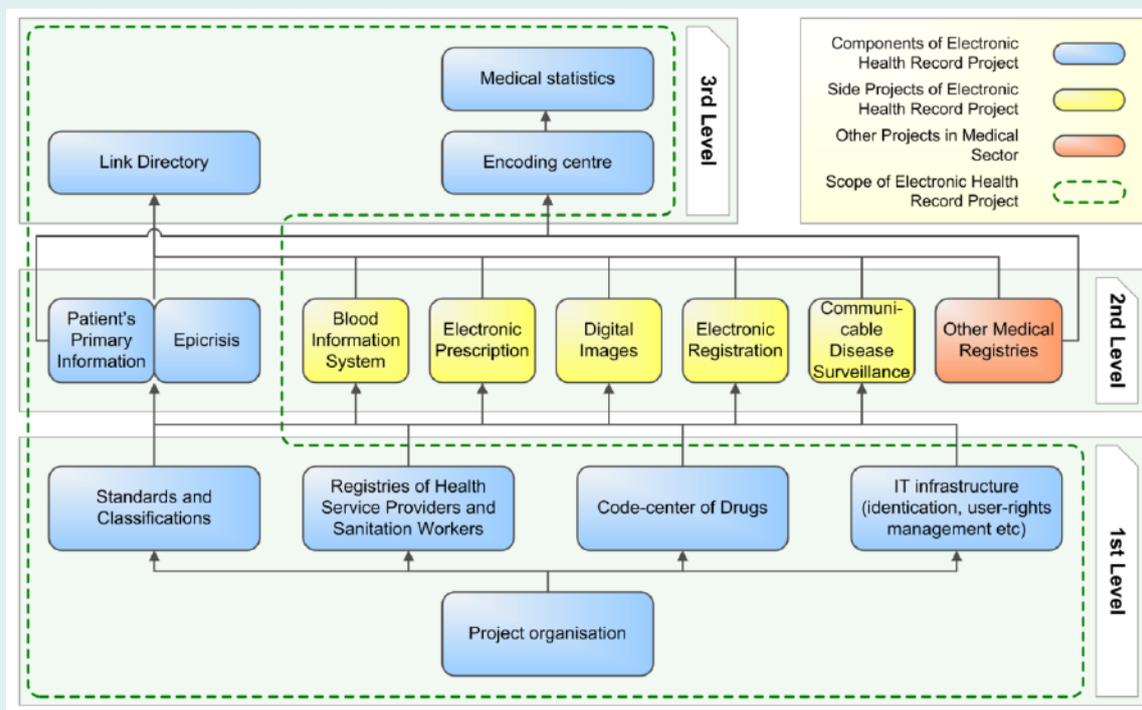
Based on the mandatory registration of 14 documents from healthcare providers, the EHNIS database contains the following information:

- Medical records
- Critical information (cave, allergies, chronic conditions) for ambulances
- Consultations with GPs and hospitals
- Record notes from ambulant and stationary enterprise
- Link to medical pictures
- Prescribed and delivered medication (not for the care sector)
- Living will
- Next of kin information
- Organ donation
- Access log

In sum, it can be stated that the general eHealth concept in Estonia is built around the idea that all health information (structured data, not documents) should be:

- 1) Available to patients and health professionals on request
- 2) Collected once and managed centrally, so that multiple and variable secondary uses are enabled.

Figure 17. Components of EHNIS



Source: The eHealth Foundation

### 5.6.1 Infrastructure

The development of eHealth services is divided into three levels. Higher levels use services from lower levels. Therefore the lower levels must be already implemented before higher levels can be developed.

- The **first level** provides core services for all higher levels: for the EHR project and also for the side-projects.
- The **second level** consists of the most important feature of EHR – the services around hospital discharge notes and patient’s primary information. In addition there are a number of side-projects (see yellow boxes in figure 15).
- The **third Level** includes eHealth services which use data and services from first and second level, but also services that are not developed under EHR or its side projects – namely other medical registries.

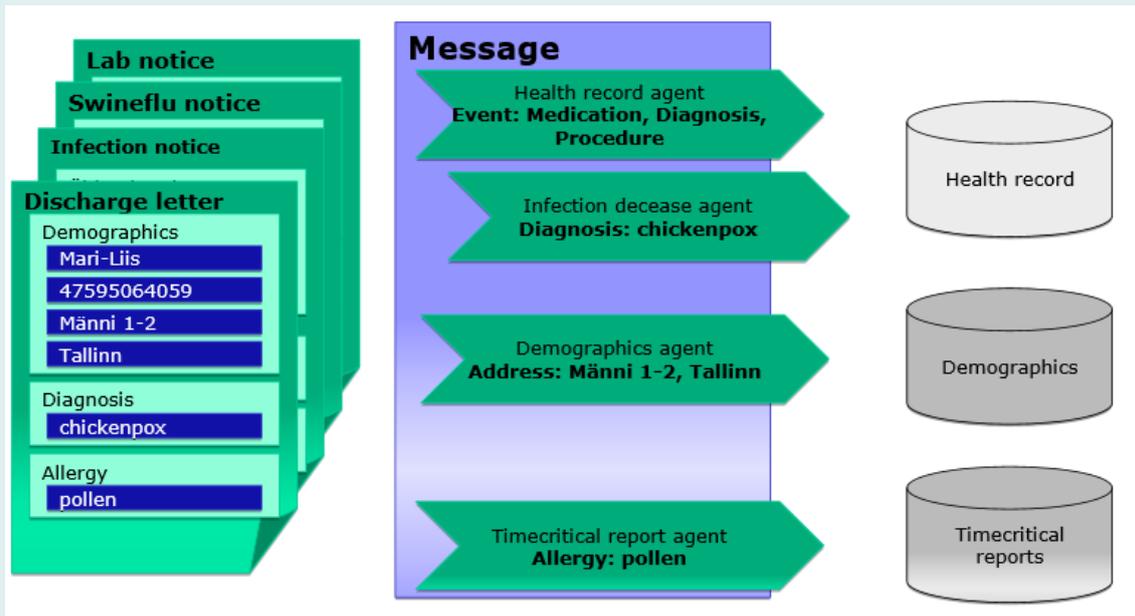
The approach is chosen to make all current and future eHealth services interoperable as they use same standards. It is more affordable to develop new services because the necessary core services are already in place. What is more, dividing projects into smaller components decreases risks.

The healthcare service providers have to conclude a contract with the Estonian eHealth Foundation in order to be interfaced with ENHIS. The individual event-based documents provided to EHR will form a person’s medical history. The local EMR system automatically sends documents to the central database.

Information systems that are interfaced with the EHR forward messages instantly, i.e. at the same time the content of the message is created and stored in the information system of the healthcare provider. The message exchange channel is a secure public [Data Exchange Layer](#).

The agent centre of the EHR exchanges all nationally approved medical documents that conform to the standard for messages. The objective of the message exchange module is to standardize the data exchange protocol and format of the health information system, the information systems of healthcare providers and the public healthcare information system.

Figure 18. Document processing in EHNIS



Source: The eHealth Foundation

### 5.6.2 Infostructure

Healthcare providers work in local EMR systems. The EHR system is a national framework with a standardized information exchange function. In order for the local system to interface with the central EHR system, and send and receive data from other enterprises, every local system needs to be updated and modified according to technical specifications described by the system administrator.

Compliance with the technical standards set by the eHealth Foundation is the main specification for the procurement of health IT systems. These included:

- Integration through the central system (Opt-out)
- Health Level Seven International (HL7) v3 (extended) for the 14 structured EHR message + ePrescription
- Documents are kept in Extensible Markup Language (XML) format HL7 Clinical Document Architecture (CDA)
- All structured data fields have Object Identifiers (OID). Only final documents are sent to the central database.
- Only final versions of clinical documents are sent into central system
- Using existing national ICT infrastructure, including:
  - ID card for authentication and digital signature
  - X-road for secure communication

Compliance with content standards in exchanging medical data is mandatory by law. To support interoperability and build an open architecture for future developments, close to all data are coded (clinical) and classified according to international standard protocols with defined lists with

nomenclature. Prior to 2013, doctors had to sign each document, now documents are approved in bulk.

- Medical history, previous illnesses and clinical status: SNOMED-CT
- Diagnosis: ICD-10
- Lab tests: Loinc
- Prescriptions: ATC

The Estonian eHealth Foundation is responsible for the standardization process of nationally approved medical document standards, classifiers and nomenclatures. This includes a web based [Publishing Centre](#) (In Estonian) functioning as a central environment for publishing medical classifiers and standards, as well as instructions for deploying messages. In addition, the centre provides EHR user and interface manuals.<sup>53</sup> The possibility of subscribing to RSS feeds is installed in order to provide a convenient way of keeping users up to date with new publications.

### 5.6.3 Privacy, Information Security, Access Control

Citizens and institutions can join and use the X-Road free of charge. An electronic patient record is automatically created if the citizen does not object to it. The centralized architecture of EHNIS means that the health information of the entire population of Estonia is gathered in one, actual location. All access rights and data usage is regulated by the law.

The Estonian Health Board manages a register for healthcare professionals. Through the assignment of IDs to every professional, status confirmation can be requested through the MISPP server (Mini Info System Portal). This portal is part of the “X-road project” and enables professionals to identify as a registered professional as well as access patient data and medical information. Healthcare providers automatically have access to the personal data in the Health Information System. However, only healthcare employees in a treatment relationship with patients have *the right* to access their health data. There is no role-based access control system in place. Instead access to EHNIS is regulated by the self-declaration of healthcare personnel, which is monitored by the government through random controls of illegitimate use. The system poses great potential risk with regard to information security and privacy.<sup>54</sup> In order to counter these, [three principles have been applied to the system](#):

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<sup>53</sup> Currently the centre is still in a testing phase, meaning that the information presented at the time can still be changed or updated during the course of work.

<sup>54</sup> Ernst and Young carried out a comprehensive risk analysis of EHR implementation in 2004. This analysis identified and assessed four categories of possible risks deriving from: technology, organizational management, public opinion and procurement partners of EHR. To minimize possible implementation risks and assure the sustainability of the EHR project's results, the following functional preconditions were established: 1) EHR should be capable of interfacing with X-tee and forward/receipt of standard (harmonized) Electronic Health Records; 2) To assure personal data protection and patient rights according to the laws, and the legitimacy of data utilization by medical personnel and authorities, users of EHR must be registered in public registers (register of Healthcare Board, Central Health Insurance Fund lists of family physicians, etc.).

1. The security risk in the central system has been diffused by several technical and administrative security methods.
  - a. The principle of complex security has been used as the basis, and according to this no simple attack on the system can cause any serious damage.
  - b. No “super administrators” can access all data without leaving any tracks of it in the central system.
  - c. The data in the central system is coded, i.e. personal data and health data in the database is kept separately.
  - d. All data stored on the drive has been encrypted and is accessible only through a special security module of the database – this will exclude data leakage in the event the drive is stolen or illegally copied.
  - e. Activities are monitored.
2. Secure authentication is used for all users of the EHR – requiring an ID card, mobile ID or other similar method. Password based authentication is forbidden in the EHR since this method is considered vulnerable to Trojan attacks.
3. Maximum security principle is used in the event of all data stored in the EHR. All activities in the system, such as adding, changing or viewing data, will leave tracks that can't be changed later. This enables patients to view who enters their record through the patient portal. In order to prevent any malicious changes, all documents stored in the central system have digital signatures of people who compiled or sent the documents, or it must be date stamped by the healthcare service provider's information system.
4. The patient or a patient's representative with full legal rights has the right to enquire about all documents relating to the patient from the EHR information system that the physician has not set any restrictions on. A patient representative with full rights has complete authorization to act on behalf of the patient. The patient doesn't have a right to change the level of authorization of a legal representative.

Every Estonian has a Personal Identification Code (PIC), which is included on the certificates of their eID cards. PIC is provided by the Population Register. Citizens can access their own health data through the Patient portal, where they can also declare their intentions and preferences. The patient has a right to set access restrictions to documents, cases of illness, and to all his/her information in the EHR. The access ban can be set to specific documents or applied to the complete data in the EHR.

#### 5.6.4 Shared eHealth Components and Services

The central database stocks information which is urgently needed for the treatment of the patient, as well as information required for national and medical statistics enabling better and more efficient healthcare planning, organization and financing. Two types of data are included:

- Patient's primary information (contact information, insurance information, allergies, important drug information, etc.)
- Link directory that points to other sources which include medical data about the patient (for example IT systems of hospitals and GPs)

[The ePrescription module](#) has a prescription database at its core. It replaces paper documents and includes prescription and purchasing information and automated discount calculations. It is interoperable with the EHR and links to the pharmacy information system, which transfers

purchasing information to the prescription database. The doctors' information system also links to the prescription database and to the health insurance fund information system, where the discounting function operates.

**The digital images module** provides access to medical images for all healthcare providers. The medical imaging information system is interoperable with the EHR to provide access to results. It also links to the imaging archive of medical images that in turn links to the EHR.

**The digital registration module** includes a unified patient registration system and information about patients' waiting times. Patients use the patient portal to register and access registration and waiting list information. The portal links to the registers of healthcare providers and doctors and specialists to provide this information to patients.

### 5.6.5 EHR Landscape

Four EHR system vendors for hospitals in use in Estonia. All four systems are delivered by national vendors. Only one of these systems has integrated functionality for decision support based on medical data, lab results and classifications.

Four EHR system vendors for GPs. One vendor holds 80 % market share.

The care sector is not linked up to the EHNIS and its services.

### 5.6.6 Digital Services for Citizens

Estonia has two types of patient portals, one national and one for the hospitals of which the latter is the one most used. The national portal offers access to:

- Illness data from healthcare system
- Self-monitoring data
- Wellness data from third parties
- Data from social system
- Patient forums
- Screening reminders
- Decision support
  - Self-care
  - Virtual health check

### 5.6.7 Secondary Use of Data

During our information searches, we have not been able to identify specific discussions on the use of secondary data.

## 5.7 Final Reflections

The Estonian X-road infrastructure and the EHNIS project attracted much international acclaim for its innovativeness following its launch. EHNIS was expected to bring about positive changes in terms of saving time, quality and expense control as more things get documented in standardized ways.

Among its key success factors, it was commonly pointed to the overall approach taken to an eHealth project. The EHNIS project was not introduced as a large IT project, but was rather described as a

societal development project in which alongside implementation of new information technology concepts, it also included aspects of medical, as well as technical standardization, ethics and legislation. In particular, the development of a legal foundation was seen as a key success factor. An amendment to the Health Services Organization Act with a new chapter on the Health Information System legally defined the need for a health information system, and gave a clear political framework for the work.

While Estonia used to have a relatively strong position in eHealth development as compared to other countries, it has probably lost some of its lead in the last years. Mainly these are explained as having to do with financing, lack of benefit realization and the Ministry of Social Affairs lacking an active governing role in the project.

In hindsight, the initial financing from the EU Structural Fund was a small proportion of the cost of implementing, operating, and further developing ENHIS. The main challenge of ENHIS remains the future financing of the initiative and the whole operation of ENHIS. A main reason for the relatively rapid development of the ENHIS was the deadlines inherent to the external financial framework provided by the EU Structural Fund. As an example, the Fund provided 640 000 Euro for IT training of healthcare personnel. That stimulated a rush to finish training of about 9000 employees in less than half a year because the eligible financing period was about to end. Thus, while demonstrating a tremendous capacity for mobilizing action, the example also demonstrates the challenge of long-term financial sustainability of the ENHIS project – being so critically dependent on international funding.

Another key challenge for the ENHIS project has been the lack of outcomes evidence. In general, there is a positive attitude towards eSolutions in Estonia, which also had positive effects for the ENHIS project. Lack of hard evidence on actual achievements and signs of poor consensus on critical matters raises increasing doubts about the final result of the project. This has opened the floor for more critical voices, such as the Estonian Medical Association (EMA). EMA is critical to anticipated effects of ENHIS with regards to efficiency and quality improvements. They argued that the doctors' responsibility for updating the central database would in fact introduce a burden on their time. What is more, EMA was also skeptical that the patient's access to medical notes would make doctors more cautious about medical assessments and documentations of these, in fear of being sued by patients for being wrong. This could reduce clinical quality.

In 2014, the [National Audit Office](#) released a report<sup>55</sup>, recommending that the Ministry of Health and Social Affairs deal with the eHealth deployment more forcefully, as initially planned objectives have

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<sup>55</sup> The report is only available in Estonian, we have used the summary of the report, together with news items as our sources for this section.

still not been achieved.<sup>56</sup> 15 million euros had been spent on the development of eHealth, instead of the initially planned 2.8 million euros.

It was noted that data in the eHealth system cannot yet be fully used for treatment purposes, national statistics, registry-keeping or monitoring. The National Audit Office was of the opinion that the EHR has not taken off as planned, because data was not entered in the system, although this had been required by law since 2008. For example, 92 % of providers of specialist medical care services (including hospitals) did not send any data to the EHR in 2012 and half of those who did, only sent a quarter of the required data. Without data being sent to the EHR, the record cannot be used in everyday treatment and the broader goal of eHealth, which is to make the organization of health more efficient, cannot be achieved. The National Audit Office criticized official authorities for not imposing sanctions for failure to send documents to the EHR. While registration of data in the EHR increased during 2013, there were very few instances of data actually being viewed. Another concern was with the quality of the data, and the practice in which enterprises submitted documents that did not adhere to national standards, thus making them incompatible for automatic processing.

The eHealth Foundation has been responsible for the EHR, Digital Image and Digital Registration projects. Digital Registration, which was completed in 2008, has never started to work. There is still no central system booking a doctor appointment at hospitals. The audit report explains this with lack of interest among health service providers. Digital Image is still not a database in which all medical images are stored. Digital Image is simply a place where references to the locations of images are stored. The image itself cannot be viewed in the system. Also, not all health authorities submit references to the locations of images. One of the reasons for this is that two regional hospitals established by the state started developing their own system – the Image Bank – at the same as Digital Image was created, and 80 % of the medical images taken in Estonia are currently located therein. This means that Digital Image has little value at present, as the images are located elsewhere and they are also viewed and used elsewhere.

The National Audit Office is of the opinion that the reason for these failures is the lack of an active strategic role in the supervisory board of the eHealth Foundation. In addition, the activities of the Foundation are considered to have been too many and too dispersed. In addition to the main eHealth projects, several other services were developed at the same time, such as eConsultation and eAmbulance. Development of additional services reduced focus and dispersed funding. However, it should also be noted that the development of services using the central database might have been

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<sup>56</sup> The objective of the audit office was to assess whether the objectives set for eHealth – a higher quality of health service and the more efficient organization of healthcare – had been achieved. The four main eHealth projects were reviewed in the audit. The problems encountered in the development and implementation of eHealth and their reasons were also investigated. No opinion on the completion of eHealth in terms of IT or its security was given in the audit.

critical for demonstrating the potential benefits of the centralized system, thus, ensuring support for the bigger, long-term project.

ePrescription is the only solution created by the state that is actively used. The NAO report points out that ePrescription was developed by the Estonian Health Insurance Fund. The fund kept the focus on one major project until it was implemented.

NAO recommended that it is necessary to terminate projects that are not working before new projects are launched. Furthermore, the government had to demand that all health service providers submit data and use the system.

Following the audit report, the Estonian Government has set up a task force for eHealth, and in 2015 released a national eHealth strategy (Only available in Estonian).

## 6 The Netherlands

### 6.1 Demographic Data and Political Tradition

Population (2013)	16 804 224
Area (km <sup>2</sup> )	41 543
Political tradition	Unitary parliamentary constitutional monarchy
Administrative levels	State, province, municipality

### 6.2 Key Figures for Healthcare System (2011)

Health status	
Life expectancy at birth (years)	81.2
Expenditure on health	
In percent of GDP	11.9
Per capita (USD purchasing power parity)	5 099
Public financing (% of total expenditure)	85.6
Private financing (% of total expenditure)	14.4
Health workforce	
Practicing doctors (per 1000 population)	3
Practicing nurses (per 1000 population)	11.8
Healthcare activities	
Doctor consultations (per capital per year)	6.6
Hospital discharges (per 1000 population)	122
Total hospital beds (per 1000 population)	4.66 (2009)
Average length of stay, all causes (days)	5.8
Access to healthcare	
Coverage for healthcare (% of total population)	99.9
Out-of-pocket medical spending (% of household consumption)	1.5

Source: OECD 2013

### 6.3 Gathering Information on the Dutch Case

Documentation for case study was gathered in two phases:

Desktop research, May-June 2013 and January-March 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background information on the Dutch healthcare system, eHealth strategy, key actors and initiatives.

Study trip, October 2013: 17 participants (12 Directorate of Health), (1 Ministry of Health and Care Services) (4 healthcare personnel). The study trip was organized around the following program:

## NORWEGIAN STUDY TRIP TO THE NETHERLANDS, OKTOBER 2013

Monday 7.10.2013	National ICT Instituut in de Zorg (NICTIZ), den Haag
Tuesday 8.10.2013	National Implementatie Agenda (NIA), Utrecht Ministry of Health, Welfare and Sports, den Haag
Wednesday 9.10.2013	R-EPD at Libra Rehabilitation, Eindhoven
Thursday 10.10.2013	Epic, s'Hertogenbosch Amphía Zuikenhuis, Breda

On the basis of the information gathered throughout the study trip, the report was revised focusing on the Dutch experience with realizing policies in practice. The description that follows is by no means exhaustive. The content of this report reflects the knowledge needs of the Norwegian One patient – One record program. When situated perspectives and viewpoints are expressed, we highlight this by referring to the source. To validate the findings, the Dutch host institutions have been invited to add comments and corrections to the report.

### 6.4 Financing, Governing and Organizing Healthcare

#### Key Components of the Dutch Healthcare System

##### Exceptional Medical Expenses Act (AWBZ)

A public insurance for long-term care (e.g. elderly care and care for mentally and physically disabled), mandatory for the entire population, regulated by the government and executed by administration offices that bear no financial risk.

##### Health Insurance Act

Private insurance for curative care (e.g. primary care, inpatient and outpatient hospital care and prescribed drugs), mandatory for the entire population, regulated by the government and executed by private insurance companies (i.e. the former sickness funds and private health insurance companies) who bear substantial financial risk.

##### Supplemental Health Insurance

Private insurance for supplemental benefits (not covered by the other two components, e.g. comprehensive dental care and physiotherapy), no regulation by the government and executed by private insurance companies (who bear full financial risk).

The Dutch healthcare system consists of three parts (see table X) and can be described as hybrid system with public, private, volunteer and professional elements.<sup>57</sup> Constitutionally, the Dutch state is responsible for the universal accessibility, quality and efficiency of healthcare. However, the government's role in actual provision is minimal. Following the principal of subsidiarity an array of

<sup>57</sup> For more information about the Dutch healthcare system, see i.e.: [http://www.mof.go.jp/english/pri/publication/pp\\_review/ppr016/ppr016c.pdf](http://www.mof.go.jp/english/pri/publication/pp_review/ppr016/ppr016c.pdf) and/or <http://ifwj.org/e/wp-content/uploads/2012/07/Dutch-cure-and-care-Feb.-2012-F.pdf>

actors - for profit, non-profit, volunteer, and professional - are involved in the policy formulation, financing, and implementation processes surrounding healthcare. As a result, the Dutch healthcare sector does not have a single power center that can interfere unilaterally in the organization of healthcare. Instead, the Government has delegated public regulatory authority to the various associations of providers, insurers, trade unions, employers, professional groupings and a number of (ideological/religious) volunteer organizations. The actors are mutually dependent on each other and have traditionally collaborated under the label of corporatism known as the “Dutch polder model” which emphasizes collaboration and consensus-making over conflict.

### ***Introducing a market-oriented healthcare reform***

In 2006, the Government introduced a new market-oriented healthcare policy reform. The reform seeks to combine the introduction of competition elements with the realization of a right to health. The main objective is to make healthcare more efficient and affordable. The result is a private health insurance system with strong public “safeguards” (solidarity principle, accessibility guaranteed by law; coverage by legal regulation; pooling).

**Patients:** hold a key role in this market-regulated system, the critical consumer will act as a driver for quality and cost effectiveness.

**Service providers:** will deliver healthcare of high quality for an affordable price.

**Insurance companies:** should assure that consumer demands are reflected in the services offered by providers by contracting providers on price, volume and quality to lower costs.

**The Government:** oversees quality, availability, and costs and negotiates what should be included in the basic insurance package.

**Innovation:** will increase as service providers and insurance companies will need to develop better services for a lower price to attract healthcare consumers.

Nine Dutch (non-profit) insurance companies offer access to a range of service providers. In general the degree of patient mobility is low, both among insurers and service providers, the tendency is that patients choose insurers and providers located in their home region.

Healthcare providers negotiate with insurance companies on the basis of volume and (partly) price. According to the Dutch [Association of Dutch healthcare insurance companies \(ZN\)](#) the system still needs to mature. It is too early to conclude on the effects of the reform when it comes to improving the quality and cost effectiveness of healthcare.<sup>58</sup>

In order to enable comparison and support, the commissioning work of insurance companies’ quality measurements have become key. [The Zoorginstituut](#) is responsible for defining and measuring the

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<sup>58</sup> An important exception is the use of generic medications, in which reduced costs are documented.

quality standards in the market and for sanctioning when needed. All service providers are measured according to the same areas and standards. Results are published broadly.

To stimulate competition between service providers, the system allows insurance companies to buy single services, without having to buy the entire range of services from one provider. In order to stand out in the market, providers will then have to focus on the quality of each and one service area.

The Netherlands scores high on the [ranking of healthcare services in Europe](#), including public health and preventive work and patient involvement. The Dutch are positioned at the top of the Euro Health Consumer Index for the third year in a row. Short waiting time and high equity of services are among the success factors. In addition, it is worth mentioning that the Dutch has a significant [high level of investments made in Health and Natural Scientific related R&D](#).

### ***Demographic trends and ongoing policy debates surrounding healthcare***

Cultural plurality, market-driven competition, and consumer choice are key principals for Dutch public administration, also within healthcare. As a principal, all forms of treatment and care shall be differentiated and tailor-made for the individual. This results in a healthcare insurance system that is experienced as expensive for the citizen. Today, an average Dutch family pays 11.000 euro a year on healthcare, which is about 1/4 of their annual salary. If costs continue rising at this speed the next ten years, the average family will spend about half their annual salaries on healthcare in 2040.<sup>59</sup>

Against the backdrop of the European financial crisis the universal model based on the solidarity principal is under political pressure. It is therefore seen as necessary to organize healthcare in new and better ways in order to cut costs without reducing quality standards. Two interrelated issues are high on the political healthcare agenda in the Netherlands:

- Drawing the line between *cure and care*
- Innovation as a tool for a more cost efficient healthcare system

### ***Drawing the line between cure and care***

The financing model for healthcare is subject to political debate. The Government points to what they have called «the information paradox» in the sector. The argument is that people, in a time of increasing access to health related information have a tendency to medicalize problems that can be solved outside the healthcare system. To counter this tendency, a revision of the legal framework is revised.

Care, including preventive work and coordination of efforts surrounding disabled people and the chronically ill, is currently regulated by the Exceptional Medical Expenses Act (AWBZ) and organized and financed by central government through taxation. A large sum of the expenses covers the costs for long term care for elderly, chronically ill and disabled people. By 2015, the government seeks to

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<sup>59</sup> The estimates is taken from the Dutch Minister of Health, Welfare and Sports speech [«Van system naar mensen»](#), published 8<sup>th</sup> of February 2013.

establish a separate legal framework and financial system for these patient- and user groups. With the new law, the government foresees that a large sum of the expenses that are today defined as basic healthcare services will be redefined as care.

At the same time, to make the care sector more efficient insurers are invited to offer insurance packages containing home nursing services. Home care such as cleaning and personal hygiene is to become the financial and organizational responsibility of the municipalities. The government maintains its responsibility for the most fragile patients, but otherwise reduces its role to defining and overseeing quality standards for service provision.

In the swirl of this de-medicalization process, the Government expects that patients and their families, and local communities takes a larger share of the responsibility for the execution of care. Volunteer organizations, social networks and communities are being mobilized as new important actors and arenas for (unpaid) care work.

Given that the Dutch healthcare sector is such a hybrid mix of private and volunteer actors, there is a risk that the distribution of responsibility to insurers, municipalities and the social networks of the patients might lead to increase socioeconomic differences in terms of access to high quality care.

### ***Innovation as a tool for a more cost efficient healthcare system***

Rising demands and costs of healthcare combined with personnel shortage (estimated 480.000 in 2020) is a key challenge for the Dutch healthcare system; a challenge for which innovation is seen as an important problem solver.

Innovation in healthcare has been an important strategic area for a long time in the Netherlands.<sup>60</sup> With reference to the earlier mentioned «information paradox», the Government points to an imbalance in the innovation system. Product innovation occurs too fast, we are offered more and more ways to treat diseases, which leads to rising costs. Process innovation evolves too slowly. Service innovations such as online booking and eConsultations should be developed and replace, not supplement existing practices in order to make the delivery of healthcare more (cost) efficient.

In 2008 The Government launched a program for innovation in healthcare. Taking as the starting point the demographic trends and the financial development a platform was established (Zorg Innovatie Platform - ZIP). The platform had 15 expert members and was led by the minister of health, welfare and sports. Work was organized under three headlines:

- The person at the center: strengthen the position of the patient and the professional
  - Strengthen the possibility for self-managed care
  - Organize health and care in networks around the patient and in relation to the patients social context (work, family, friends, leisure activities, etc)
  - Preventive work

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<sup>60</sup> Innovation is categorized as: *strategic innovation, product and service innovation, process innovation, incremental (process) innovation.*

- Exploit the potential of ICT
  - Attract and keep qualified healthcare personnel
  - Strengthen expertise and competence among healthcare personnel
  - Focus on innovation as part of provision of life-long learning
- Smarter organization of healthcare services
  - Stimulate the uptake of eHealth solutions and ICT as a labor reducing component
  - Stimulate debate between patients, providers, insurance companies and industry throughout the entire ICT sector

With the focus on innovation, eHealth is brought to the fore of Dutch healthcare. In Dutch public documents eHealth is defined as; *the use of ICT to enable improvements in health and care services, in particular when it comes to issues of Accessibility, Quality and Cost effectiveness.* To develop a further understanding of the Dutch eHealth system, in the following we will first give an overview of recent history and key actors. Then, we move on to describing the main components of the system.

### **6.5 Dutch eHealth: Past, Present and Future**

At the end of the 1990s a plan was made to develop a national EHR system in the Netherlands. The aim was to enhance the quality of healthcare and strengthen patient safety by developing a shared patient record that would make all relevant and updated patient data available for patients and healthcare personnel regardless of time and place and in a secure and safe manner.

Today, at the Parliament's request, the government is no longer involved in the national EHR project. Uncertainty prevails with regard to what will be the financial and operable future for Dutch eHealth. In the following we will give a brief overview of this history.<sup>61</sup>

#### **Timeline**

**1996:** Growing awareness of the challenges surrounding use (or lack thereof) of IT in the healthcare sector. Challenges arising from i.e. lack of patient centered systems, lack of integration across levels of healthcare, outdated regulatory framework, limited IT competence and low quality IT products. As recommendation is made to develop a patient chip card, open an information highway (internet+), and develop a national EHR.

**2002:** Ambitions are modified. Rather than a national EHR system in itself, the aim is to develop an infrastructure for exchange of messages. The concept is to build a system that leave the patients' medical record at the source, and offers the various actors connectivity - rather than central system building. The [Nationaal ICT Instituut in de Zorg \(NICTIZ\)](#) is established (ca. 40 employees) to develop the technical infrastructure, EHR standards, and guidelines/roadmap for realization of national solutions.

**2006:** the national infrastructure - [AORTA](#) - is developed. Plans are made for additional applications:

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<sup>61</sup> The main source is NICTIZ.

- Electronic medication record to provide healthcare personnel access to an updated list of prescribed medications through the patient record. ePrescriptions, contraindications, intolerances, and allergies to be included incrementally.
- Electronic General Practitioner's Record (WHD) gives the ER doctor access to recorded notes from the patient's five latest GP outside office hours. The WHD is a strategically prioritized area due to problems with recruiting GPs.
- Other plans PHR with access to patient record, ePrescription, acute care record, electronic diabetes record, electronic child record, pregnancy record.

**2007:** The integration platform "Landelijk Schalkepunkt (LSP)" is operable and functions as a national *switchboard* that gives authorized personnel access to relevant information for treatment of patient outside their own healthcare organization.

**2009:** The Dutch parliament passes a bill that makes it mandatory for healthcare providers to connect to AORTA. A public campaign is initiated, with a public letter explaining about AORTA and the possibility to opt-out. 330.000 people (2 %) opt out. The GPs expresses reservations to the AORTA.

**2011:** The bill on the national EHR is rejected by the Senate, which also demands that the government immediately stops further involvement in the project. The main argument against AORTA surrounds the implication of the opt-out solution on privacy issues. 8 million references to health records that had been linked to the AORTA are erased.

**2012:** National Implementation Agenda for eHealth (NIA) (In Dutch) is established representing the financiers, providers and users of healthcare services:

- KNMG – The Royal Dutch Medical Association – federation of seven doctors associations.
- NPCF – The Dutch Patient-Consumer Federation (In Dutch) umbrella organization focusing on patients' rights and patients' involvement in the healthcare system.
- Association of Dutch healthcare insurance companies (ZN) umbrella organization for all healthcare insurance companies.

NIA sets out to act as a coordination point for Dutch eHealth. The aim is to eliminate common barriers and jointly complete the essential preconditions for successful development and implementation of eHealth.

A sector coalition VZVZ (In Dutch) takes over the financial and managerial ownership of AORTA.<sup>62</sup> A two-year plan is drafted to establish AORTA in the market. In accordance with existing legal framework, an opt-in principal replaces the opt-out solution. The objective is to:

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<sup>62</sup> This entails that NICTIZ is split in two. The branch working on the development and operation of the AORTA infrastructure now is moved into VZVZ and financed by sector actors. The branch working on standards, advice

1. Make healthcare personnel connect to the infrastructure
2. Recruit patients
3. Build content

**2013:** In a speech to the Senate, the Minister of Health, Welfare and Sports «[from system to people](#)» (In Dutch) the importance of eHealth in the healthcare system is confirmed and NIA is recognized as the national action plan for, and by the sector. The government limits its role to develop regulations (EU directives in particular), (international) standards, guidelines, and reimbursements schemes for digital services. No new national eHealth strategy is to be developed.

NICTIZ, NIA and the Ministry of health welfare and sports launch an annual [eHealth monitor](#) (In Dutch). The monitor shows implementation status of key eHealth solutions, financing, standardization, public awareness and governance.

Today, connection to AORTA is voluntary. Currently, (January 2014) 75 % of GP practices, 90 % of Locum practices, 83 % of pharmacists, and 22 % of hospitals are connected to AORTA and 2.3 million patients have given explicit consent to make their GP record or pharmacist record available for future consultation by another GP or pharmacist. Next to AORTA, there are several local and regional infrastructures that operate with different standards from AORTA. This implies challenges with regard to system integration. Also it is not clear whether AORTA will become *the* national connection point, or what forms of applications will be built on the infrastructure.

#### **Evaluating the Dutch National EHR project**

Evaluations of the project point to factors like technical ascendancy, lack of political backing, and Dutch regulatory history when explaining why the National EHR failed to realize.<sup>63</sup>

According to evaluations from NICTIZ and NIA, the national EHR project was **too focused on technical implementation**. In preparing for the development of the infrastructure and its applications the project did not take use of process oriented studies or work flow analysis from healthcare settings. At the start the National Association of General Practitioners, a member of the federation KNMG, was involved in the governance of the project. In 2005 the government decided to take full control of the project and control the process top down in order to speed up the process. This concurred with the government introducing plans to reduce costs of healthcare. In sum, causing strains on the relationship between the government and professional organizations. As a result, professional organizations did not feel commitment and co-ownership over the EHR project and GPs expressed reservations towards use during the Parliamentary debate on the EHR law.

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and information dissemination on eHealth continues under the NICTIZ label, and is still funded by the Government.

<sup>63</sup> Source: NSOB report “Het EPD voorbij” (2012: ‘Beyond EHR’).

In hindsight, it is clear that the national EHR project was marked by **lack of end users involvement in needs assessment and decision making processes**. As a result, the project failed to identify and prioritize needs. The rationale for public investments and legal reforms remained unclear both for professional groupings, policy makers and the public. Different opinions figured on the content of EHR and for whom and for what it was to be used. As a result, the national EHR program meant something different for everyone. With a technical infrastructure ready developed, but without a clear (sector) identity for the project and the solution, in the final phase of decision making it became clear that the national EHR project did not have sufficient political and professional backing to make connection to AORTA mandatory.

The Dutch have traditionally been critical to storage of information in a central infrastructure.<sup>64</sup> Deliberations in Parliament and Senate focused on the **legal, security, and privacy risks** involved in a national solution. The choice of an opt-out solution was criticized for threatening patient autonomy with regard to control over the access to his/her health information. During the public debate, the project did not manage to mobilize professional advocates that could contribute to a more balanced debate by voicing the potential benefits of the national EHR project with regard to increased patient safety and quality of care.

### ***Moving forward – the future of Dutch eHealth***

While the government decides to retract from the national EHR project, it continues to recognize eHealth as an important tool for the making of a more cost-efficient healthcare system. However, it is left to the stakeholders and the healthcare market to decide whether, and in what form eHealth should be a part of healthcare.

The development of the AORTA infrastructure, including the access control system (register + card) is estimated to 300 million euros over a period of 10 years. In addition are costs for annual operation and maintenance costs for about 10 million euros + costs of reimbursing healthcare providers who enrol as users.<sup>65</sup>

The NIA collaboration can be understood as a response to the absence of strong central governance on eHealth. NIA attempts to balance market forces by bringing a broader range of voices and concerns to the decision-making processes surrounding the digitization of healthcare.

The starting point for NIA is the agreement that quality, responsibility and sustainability within the sector is closely connected to the development of eHealth. The actors are devoted to develop a collaboration that is to the point, pragmatic and action oriented. The NIA platform is shaped around

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<sup>64</sup> This could be understood in the light of the 2<sup>nd</sup> world war sociopolitical history and the persecution of the Jews.

<sup>65</sup> In 2006, at the start of the project, a cost benefit analysis was done. The result was met with skepticism and critique as it was seen to lack a clear substantiation for the linkage between program and assumed positive effects on quality of care and innovation. In addition, the analysis was not able to give a clear result with regard to distribution of costs and benefits among different actors, analysis was considered flawed by too many unknown variable in capability.

initiatives that all parties can agree on, they do not bring in controversial cases. This strengthens the legitimacy of the cases that make it to the NIA.

The partners have developed their respective agendas on eHealth reflecting their idiosyncratic interests. The agendas (respective and shared) are revised and tuned annually to ensure progress and coherence:

- **Insurance companies:** Streamlines commissioning work and procurements in such a way that the content- and quality standards of insurance packages are clearly communicated for healthcare providers.
- **Healthcare providers:** Ensure that digital solutions are in line with clinical guidelines and protocols.
- **Patient and consumers:** Work for accept of eHealth and ensure that patients are sufficiently involved in the development and implementation of specific solutions.

For the first period (2012-2015) the shared platform focused on dissemination work, upscaling of successful initiatives, telecare for chronic care patients, using ICT to strengthen 1<sup>st</sup> line of service and collaboration throughout the sector, eMental, eConsultation, and developing long term plan for R&D activities within eHealth.

The 2013 eHealth monitor highlighted the need for development of shared solutions for information exchange and solutions that give patients' digital access to their patient record. The monitor also showed that it is necessary to continue to build awareness on the potential of eHealth among health consumers and healthcare professionals to mobilize support for the eHealth project. Consequently, the NIA platform is strengthened with three new partners:

- [De Vereniging van Zorgaanbieders voor Zorgcommunicatie \(VZVZ\)](#) (In Dutch) – responsible for the AORTA infrastructure - VZVZ represents healthcare providers and ICT vendors. The [Nationaal ICT Instituut in de Zorg \(NICTIZ\)](#) - national knowledge centre for IT and innovation in the healthcare sector. Mainly involved in work on standardization, monitoring, advising and connecting stakeholders - Nictiz will contribute with knowledge and expertise on standards.
- [The Zoorginstituut](#) - The Healthcare Insurance Board plays an important role in maintaining the quality, accessibility and affordability of healthcare in the Netherlands. Mainly involved in work on managing the basic healthcare package and quality standards and monitoring - CVZ will contribute with focus on public interest

The expanded group of partners has published a shared covenant on governance in which target areas for 2014-2017 are listed:

- Primary care
  - Make new eHealth definitions and products: Patient self-management; ICT applications, scaling up and removing barriers
- Specialist care
  - eHealth implementation
- Mental healthcare
  - Promotion of eHealth implementation: making plans before Q12014

Both NICTIZ and NIA are concerned with development of ground rules with regard to the governance of Dutch eHealth. On a regular basis, NIA has informal meetings with the Ministry of Health, Welfare and Sports in which topics of national interest can be addressed. The meetings take the form of mutual informing, not decision-making. However, without a strong governmental role, there is a need to find some sort of shared standard that can guide eHealth development. NICTIZ proposes to discuss an initiative similar to the US “Meaningful use”.

Having introduced the broad framework for Dutch eHealth and its history, in the following we shall focus on some examples of how actual EHR solutions are being developed and taken into use in the Dutch healthcare system.

## **6.6 Current National Dutch eHealth System**

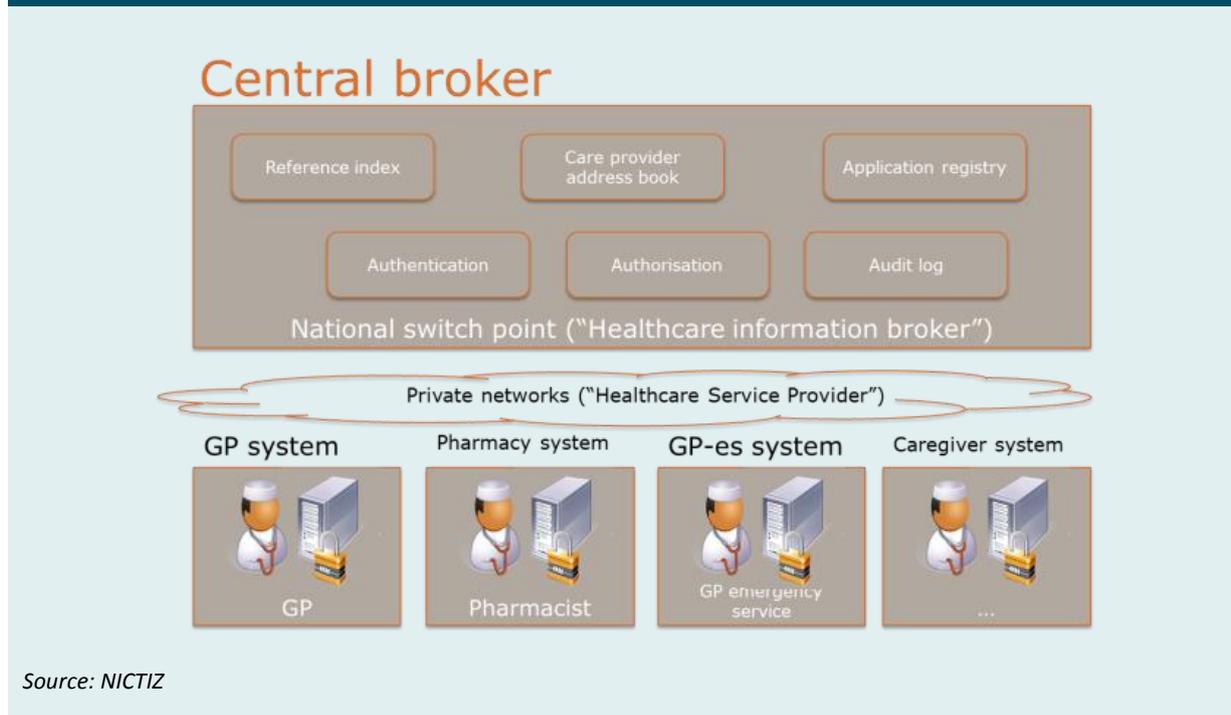
As a concept, the national AORTA infrastructure facilitates coordination through data distribution with the option of requesting information and is a health information exchange type of solution. The solution will provide the information but have no functionality or process support for patient trajectory between different organizations.

### **6.6.1 Infrastructure**

In the Netherlands the actors in the healthcare system use different, private networks and encrypted connections. There is not one dedicated national health network.

AORTA is a generically designed infrastructure for message exchange that contains a reference index mechanism and standardised message formats. Process support or decision support is not part of AORTA, and is addressed in the healthcare applications, like EMR-systems. AORTA is based on a National switch point, the integration platform «Landelijk Schakelpunt - LSP». The LSP provides an overview of healthcare providers and a central reference index that keeps track of which healthcare provider has information about the patient available for consultation, and for which availability the patient has consented. The AORTA concept does not entail a centralized patient record system, nor is it an integrated patient record system. The original source records stay with the healthcare provider responsible for patient treatment. Summaries from source records at the General Practitioner are accessible to authorized locum GP's. In order to make it possible to search and request relevant information across enterprises a national reference index (VWI) has been developed that maintains a set of links to different patient records. The result is a partly de-centralized system.

Figure 19. AORTA architecture



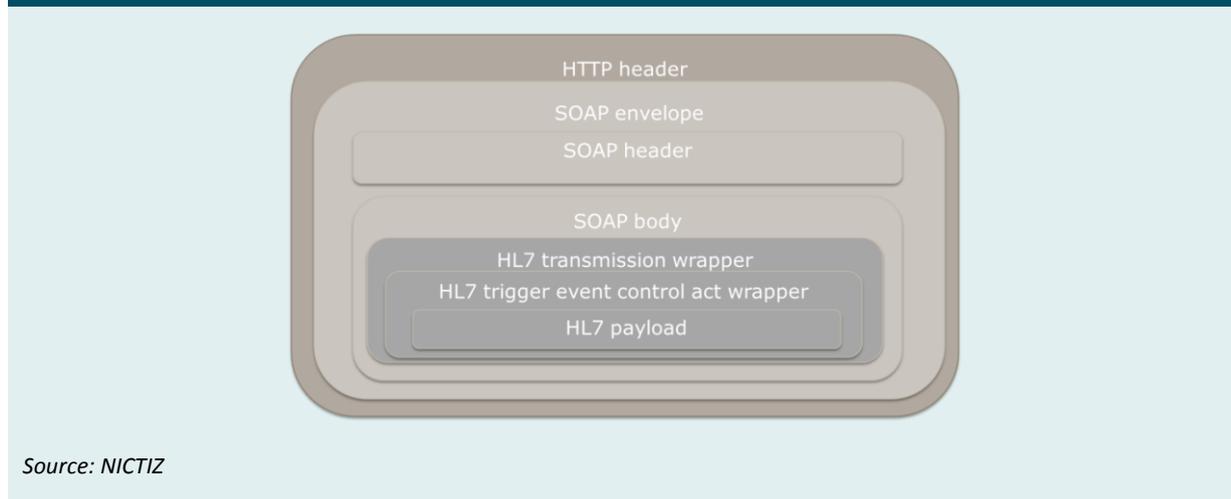
Source: NICTIZ

Connecting to the AORTA is now voluntary, and both the Doctor and the patient have to opt-in. In order for a system to be connected to AORTA, NICTIZ assess and qualifies the system and the vendor.

### 6.6.2 Infostructure

There is no shared information model established in the Netherlands. The AORTA system is based on the use of messages for the communication of information (see figure 19).

Figure 20. AORTA message structure



Source: NICTIZ

Work on standards is regarded as key for the further development of eHealth. Where they exist, existing standards are to be used. On demand, new, shared standards are to be developed. HL7 v3 messages are used for the content; the messages are structured and partially coded. In addition, several old EDIFACT-messages are in use. Being early adapters of the HL7v3 standard, NICTIZ has experienced it as challenging that HL7 v3 links the information model, data structure and data definition too close together. For future implementations they would have chosen HL7 CDA.

### 6.6.3 Privacy, Information Security, Access Control

The protection of patient information and healthcare provider data at electronic data exchange is framed by legislation (existing legislation, like the Civil Code regulating the medical contract between patients and healthcare providers, also called Wgbo, the Personal Data Protection Act, and the Bill on patient rights for electronic processing of patient data), technical security: 'Well Maintained Healthcaresystem' (GBZ), control (DPA, Healthcare Inspectorate) and communication. By law, insurance companies are not given access to patient information.

Access is being controlled through a role-based system. A legal medical treatment agreement (Wgbo) is the basis and articulates the rights and obligation of caregiver and patient. Caregiver has an obligation to keep a medical file and the patient has right of access and copy, and also the right to have his medical record deleted. Only care givers directly involved in treatment are entitled to access a patient record. The patient cannot register any information in the records, but he has a right to have information added to his record, like the results of a second opinion.

A "patient" is anyone who has a citizen service number (BSN) assigned by a municipality. A "healthcare provider" is a legally protected title for a healthcare institution or individual care professional. Healthcare providers are listed in a legally established register which assigns a unique Care Professional Identification number (UZI) and a personal smartcard, protected with a pin code (UZI pass). The UZI-card has three certificates (authentication, confidentiality and electronic signature). Users connect to the AORTA by means of electronic identification of the healthcare provider (UZI-card and an authorization matrix) and by using the Citizen Service Number (BSN) of the patient.<sup>66</sup>

Unless direct action is necessary to prevent serious damage, consent in advance (opt-in) is necessary for making patient data available through electronic exchange system. The source record controller should inform patient and asks for her/his consent to make his data (a professional summary from the GP's medical record) available for consult by other healthcare providers in the future (opt-in). The healthcare provider maintains a consent registration system. The patient has the right to exclude specific healthcare providers from access to their medical data. The patient also has the right to exclude specific data from access by other healthcare providers. Electronic access is free of charge.

An authorization protocol defines access for classes of healthcare personnel. The GP can see all pharmacy records, because the GP is a prescriber of medication, but a pharmacist cannot see GP records, because the pharmacist is not a locum GP, etc. Authorization protocols are a result of negotiations in a group consisting of national healthcare organizations, and implemented by AORTA. The UZI-card contains information about position, specialization and function, and is being delivered by a PKI based professional register. UZI-server certificates are also assigned to the care institutions. Authentication of the data subject is organized by two-way authentication with face-to-face issuing

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<sup>66</sup> There is a national issued electronic ID in place in the Netherlands (DigID), however it is not on the highest security level (level 4), with only username and password for authentication. DigID is therefore not considered secure enough to give patients access to their personal health information.

of encryption key. The UZI-card is currently being issued by the national authority. According to NICTIZ, this should rather have been handled by a private company to enable a more effective registration and authentication process.

Access to AORTA gives the user the option of requesting information. The switch point authenticates and checks the authorization and routes messages between the actors. In order to connect to AORTA the enterprises must adhere to defined demands for quality and security. For the national infrastructure to work as intended, all local registers at GPs, pharmacies, and hospitals always have to be available online and the different healthcare organizations have to install necessary interfaces for search tools.

The switch point keeps an audit log which registers the act of processing, date/time, identity data subject, and healthcare provider. The controller of the exchange system is responsible for compliance. Users of AORTA has an obligation to notify the Healthcare Authority (NZA) when a suspicion of forbidden access. The patient is given access to his own data and the audit log.

#### 6.6.4 Shared eHealth Components and Services

AORTA gives access to a professional summary (**WDH**) for emergency care units and the possibility to send a report to the GP. The summary consists of data relevant for consultations:

- Visits to GP last 4 months or last 5 consults
- Chronic (current) diseases
- Prescribed medication
- Medication for which the patient is intolerant
- Allergies and hypersensitivities
- Recent examinations and references
- Other information (sick relatives)
- AORTA does not send referral notes. A private company handles ca. 80 % of the referral notes.

Medication data: **EMD**

- Earlier received medication by prescription + dose
- Pharmacists who delivered medication
- Intolerances, allergies, contra-indications
- Until 8 months back
- The system does not support ePrescription. A solution is developed, but as a result of the Senate voting against the EHR bill, has not been implemented.

#### 6.6.5 EHR Landscape

Currently, the situation in the EHR market is as follows:

- 7-9 vendors for GP systems (national vendors dominate the market)
- 4-5 vendors for hospital systems (1 national and several global vendors)
- 5-6 vendors for pharmacy systems
- Within the care sector we find a multitude of vendors and systems. It is not clear to what extent EHRs have been rolled out in the care sector.

- In the rehabilitation sector a national EHR system is currently being rolled out (national vendor)

***EHR systems among GPs – an overview from the [Dutch College of GP's](#)***

3 phases of development:

- 80's: billing and EHR
- 90's: EHR and communication
- 00's: Professional systems, decision support and communication

The level of EMR usage among GPs is high. 70 % have ASP/Web based solutions, with outsourced hosting. There is a high uptake of messaging (e.g. lab, hospital, pharmacy). Yet, besides from referrals, digital communication with hospitals is lacking. Dialogue for messages to homecare is functioning, but has a limited use of structured data.

GPs have had a reference model for EHRs in place for over 25 years and an EHR code table is established. The same goes for EHR coding guidelines (ADEPD) and communication guidelines, eg. for out of hour messages and referrals. In general, when it comes to the use of structures and codes the level of standardizations is high. Also insurance companies are pushing to get more structured data, in order to be able to retrieve statistics for reimbursement procedures and quality measurements. The Dutch College of GP's have been actively involved in the development of evidence-based clinical guidelines and the implementation of these through integration in EHR systems. As a result, the implementation of decision support tools among GPs is relatively widespread.

Currently, the focus is on development of digital solutions supporting integrated care (especially for chronic care patients) and services for patients such as eBooking and digital dialogue. When it comes to future developments, KNMG mentions the need for business intelligence solutions, more advanced decision support such as alerts when guidelines are ignored, and patient digital access to their own medical records.

With seven vendor operating in the GP market, the system landscape appears diverse on the outside. However, on the inside the concepts are basically the same. It is experienced as challenging to form a critical consumer role for the GPs. Although there are examples of GPs involved in development of EHR systems, these are sporadic cases based on personal connection rather than a systematically coordinated approach. GPs are represented in standard committees. However, the delegates are not necessarily representing innovative thinking. As a result, vendor lock-in has become a pertinent issue in the Netherlands.

**Enabling a structured GP record**

The structure of the GP record was first outlined in the 1980s. The central concept then was the "problem list". Each problem contained all information relevant to that problem (disease, complaint etc). Relevant information included record entries, which were coded using the so called SOEP structure: S(ubjective = what does the patient tell me?), O(bjective = what do I see?), E(valuation = what are my conclusions?) and P(plan = what are the next steps?). This was then further developed using various coded tables developed by the Dutch College of GPs, for example for lab results and diagnosis (ICPC-1).

In the 1990s the problem list was replaced by a more balanced concept, the episode, and along with it the GP EMR reference model. The episode represents a collection of all information relevant to a specific illness and builds further on the problem list logic. GP EHR suppliers have taken both the episode concept as well as the reference model as a framework to further develop their systems. GPs are trained in structuring their data entry using the ADEPD guideline. This guideline describes how episodes work, where data should go and how episodes can be used to maintain control over information flow within the EMR. In several projects, including the so called “EMR scan”, GP use of this guideline has been studied. Though there is still room for improvement, the adoption of the guideline and its main concepts is a matter of fact.

The table below summarizes the structure of the GP record as described in the reference model. New concepts are developed constantly and are introduced in the field. For example, prevention programs, care planning (especially for chronic patients) and e-health services.

**Figure 21. Structure of the GP record**

GP EHR	Patient record	Medical record	Episode overview
			Record items: <ul style="list-style-type: none"> <li>• Free text</li> <li>• Medication</li> <li>• Diagnostic data</li> <li>• Correspondence</li> <li>• Targets &amp; plans</li> <li>• Additional info</li> <li>• Prevention</li> <li>• Operations</li> </ul>
			Medical summary
			Attention page
	Private notes		
	Patient administration		
	GP practice record	Draft patient administration items	
		Messages	
		Prevention-administration	
		Tables & lists	
		Administration	
		Logging	
		Queries	
	Modules	Communication	
		CRM	
Billing			
Calendar			
Consultation support			
Protocol support			
Printing			

Source: Dutch College of GPs (GP reference model 2013)

### Establishing consensus on clinical pathways, patient trajectories, and decision-support tools

Clinical pathways or patient trajectories are relatively new concepts in Dutch eHealth. Most of this work is done in the hospital domain. Since the 1990s the so called “Zorgdomein service” has been a strong incentive in streamlining the referral process from GPs to hospitals. Patient trajectories are in part covered by so called Zorgstandaarden, broad guidelines that detail “best practices” for various illnesses, such as COPD, diabetes and heart failure. However, these guidelines have not been implemented using IT solutions.

Decision support tools in GP systems have been introduced since the 1990s, mostly focusing on medication. The electronic prescription of medication is widespread and various systems are in place that supports the GP in making the best available therapeutic choices. The last few years another form of decision support is of growing interest. The NHGDoc system, developed by the Dutch College of GPs, translates medical guidelines in decision rules that can support the GP during consultation. The first results of this approach are promising, though much work needs to be done to translate all guidelines into decision rules, have meaningful decision support at all times and evaluation of existing guideline decision support.

***EHR systems in the hospital sector – an overview from [the Dutch organization of hospitals \(NVZ\)](#)***

Dutch hospitals are in the process of digitization. Most of the hospitals have EHR systems but there is still much paper in use. Many hospitals are in the process of consolidating from different departmental EHR systems into a shared system for the whole hospital.

Medication is a key challenge for hospitals. There are many actors involved in the prescription of medicine, and there is no authoritative source for medication lists. About 20 hospitals have closed medication loop systems. 70 hospitals have no system at all. There is no digital communication with pharmacies outside the hospitals. Only 1 or 2 hospitals have agreed on how to describe medication by using SnoMed CT. To develop a shared language is considered pivotal for better treatment and patient safety.

Each hospital can choose freely what EHR to use. 10 large university hospitals are now in the process of procuring new IT platforms. The trend is that clinicians are getting more engaged in health IT systems, taking control of the definition of and decision making surrounding specifications for new health IT systems.

Use of decision support systems is not common. This is due to lack of structured and shared data. It is also explained by the relatively low IT maturity level at hospitals that are currently in the midst of digitization.

There is not much focus, in general, on the integration of care across the levels and actors of the healthcare system. Few digital systems support information sharing, much occurs through paper, e-mail and fax. Some vendors offer integrated solutions, but they only work if all communication partners work within the same system.

Coordinated patient trajectories are still considered a premature topic. There is no clinical demand for a shared information system, still much resistance to national EHR solutions due to the restrictions in the legal framework.

**EMR development - an example from the rehabilitation sector**

According to the Dutch national organization for rehabilitation, [Revalidatie Nederland](#), rehabilitation is defined as a process that aims to achieve recovery or improvement of people with long-term physical injury or functional impairment. Rehabilitation is characterized by multidisciplinary approach to treatment and care.

***Key figures for the rehabilitation sector***

- 91.500 patients (58.000 outpatients, 7.550 in-patients, and 26.000 consulting patients).
- Average hospitalization period is 60 days for adults, 69 days for children and minors.

- Average outpatient treatment period is 11 months for children and minors and 6 months for adults.
- 9.375 employees including 465 rehabilitation doctors / physiatrists.
- Total budget 400 million Euro

Every Dutch citizen with a health insurance is by law entitled to rehabilitation. The funding system for the private actors involved in providing rehabilitation services is based on diagnosis-treatment combinations.

The Dutch rehabilitation sector is organized through regional rehabilitation clinic offering a wide range of specialized services. Home care and ambulatory care is not as common as eg. in Norway. *Libra Revalidatie en Audiologie* is one of these rehabilitation clinics, located in Eindhoven. The clinic offers specialties within rehabilitation and audiology and employs 900 people (30 doctors), and 50 volunteers. Their annual budget is 45 million Euros. The clinic offers services to 7,442 patients in a population of 1, 5 million inhabitants.

#### **Project: Revalidatie EPD (R-EPD)**

In 2006, the 27 members clinics of Revalidatie Nederland agreed to develop an EHR for the rehabilitation sector. The objectives was

- Quality increase by new patient health record
- Efficiency increase by one way of working
- Discharge current databases
- Support for multidisciplinary team work

The project was funded by the members of Revalidatie Nederland. However, there was no existing solution offered by the market. Thus, the clinics set up a software company to develop the EHR, with a steering group consisting of professionals from different member clinics.

The project started in 2007 and in 2009 the basic design was ready. The ambition for the new EHR system was Gartner generation 4-5. The solution was first implemented at Libra Rehabilitation in June 2012 and is currently used by 2 clinics, national scaling up ongoing. The total cost of the EHR development has been 6, 4 million Euro, of which 300.000 Euros was for implementation.

#### ***Technical solution***

The technical specifications for the solutions focused on flexibility; platform independence; XML based; dynamic data model; and swift adjustable. The EHR system is built on a platform from Vital Health which is designed according to meaningful use standards. Portal is the starting point, offering users a web based solution.

#### ***Needs assessment and user involvement***

The EHR project was not primarily seen as an IT project, but rather an organizational development with a strong focus on work processes. The project involved several inter-disciplinary teams working with issues of: forms; technical capabilities; boundary conditions; and administrative conditions. The needs assessment process centered on translating the overall principals and objectives of the rehabilitation clinics (person-centered care) and work processes (interdisciplinarity) into a technical support system. This led to the following essential design elements in the R-EPD:

- 1) Process of the patient
- 2) Patient description according to ICF (-CY)
- 3) Interdisciplinary communication model
- 4) Disciplines

A pilot was first being tested, and followed by a step-wise implementation per work group. In each work group a super user was identified and a “Wikipedia” for the R-EPD was developed in order to support the transition into new practices.

Among the staff, the extensive user involvement in the content development of the system was seen as the main success criterion of the project. This helped developing shared and precise expectations and builds a strong, shared identity for both project and solution.

The basis for the development of the system is the ongoing interdisciplinary processes and aims to visualize related and mutual dependent processes and communication across the organization. In contrast to a hospital based EHR system, the R-EPD is a team based solution that facilitates multidisciplinary work while the hospital system is targeting specific disciplinary groups by providing a module for each specialty without focusing on the collaboration between specialties. The R-EPD gathers information for all disciplinary groups and gives everybody access in order for them to plan and conduct treatment in collaboration.

#### **Technical solution**

The platform that is being used (VitalHealth) is based on a three-layered architecture<sup>67</sup> that separates user interface, business logic, and data. This gives large flexibility in relation to making an own logic and own user interfaces for different user groups, at the same time as they work with the same data. The disadvantage is the amount of tailor-made solutions and maintenance needed. Version controls can be challenging, in particular if different varieties are being developed in different places.

A model-driven development is used, which makes it possible to adapt the solutions without heavy programming, simply using relatively simple modelling tools. In restricted areas, where there are no market solutions in place or where there are extensive needs for adapting solutions to different user groups this can be an adequate approach.

The system had a loose integration coupling to other systems such as PAS and accounting in which communication was run through standard interfaces (based on HL7 v2.4). This gives more flexibility to replace modules than a tightly integrated solution.

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<sup>67</sup> Three-tier architecture is a client–server architecture in which the user interface, functional process logic (“business rules”), computer data storage and data access are developed and maintained as independent modules, most often on separate platforms.

The R-EPD concept is a generic platform with a tailored made EHR system built on top. This entails that while you buy a “system”, the bulk of work is only starting once this system is to be configured to the local processes.

### **Functionality and experiences with use**

Prior to the EHR project, each professional group had their own paper based system, including a multitude of different forms. At first, the aim was to consolidate forms, but this turned out to be more difficult than assumed, thus, instead they have structured reporting in order to be able to reuse input in various forms. The resulting system is mainly document-based (structured forms) not a process-oriented system, eg. with decision support tools.

The system is considered an appropriate solution in the context of the Dutch rehabilitation sector, partly due to the IT maturity of their organizations, moving from paper based records to an EMR system. The rehabilitation clinics have developed a shared EMR system, but they have not managed to establish collaboration on configuration and standardization in the use of the system. It is up to each and one clinic to decide on how to configure the system. The clinics do not have a controlled change management process when it comes to medical procedures and implementations of these in the system.

The EHR system has implemented ICF classification coding at the top level. The system is linked to other clinical support systems eg. lab and medication. Tests scores/results (clinimetrics) are currently not integrated in the system, but must be registered manually.

Navigating in the system it is possible to see timelines and perform tag-based searches (not scanned documents).

Booking for professionals and systems is handled by a secretary. The system provides an overview of the time schedule for all staff. This is considered very helpful in coordinating the different activities in a weekly schedule.

The system does not allow for information sharing across the entire rehabilitation trajectory. The system lacks communication paths between rehabilitation clinic and primary care system, eg. functionality for admission and transfer between different healthcare providers (except the discharge note, which can be sent as an electronic message). Such transfers are done by phone or by a professional following the patient to his/her home. When a patient is released from clinic, they receive the EHR as a print out for their own, and other service providers reading.

Patients in long-term rehabilitation often have needs for coordinated services from a broad range of actors, eg. within healthcare, education, work and social welfare systems. Thus far, the R-EPD does not support cross-sectorial information exchange.

As part of the project, an attempt was made to try to build a system for patient trajectories (stroke). However, it turned out that the system was unable to support multi-morbidity cases which resulted in double registrations, and consequently was not being used by the staff.

Overall, the staff reports great satisfaction with the new system. They use less time on documentation and coordination. Each professional group document in their own area of the system, but can also access and use common areas, for communication across the treatment team to ensure

that plans are updated and coordinated. Doctors and ambulant teams operate their own systems in parallel to the R-EPD.

The clinics had managed to relate their enterprise objectives to the ICT development project, in a manner that made the project enterprise driven, not ICT driven. While they argued for the design of a custom made solution on the basis of having idiosyncratic needs, the Norwegian team did not consider the articulated needs that special compared to the needs of the healthcare service in general. What did stand out as special, was their focus on team based and patient oriented work processes, however, this is also supported by solutions provided in the market today, and did not have to be custom made.

### **EHR development - an example from the hospital sector**

The Dutch hospital sector consists of 83 General Hospitals and 8 Academic Medical Centers which together employs 180.000 (10.000 doctors). Amphia Ziekenhuis in Breda is among the three largest non-academic teaching hospitals in the Netherlands. Their focus is on education and training in broad sense, and applied research and care innovation. Top reference procedures includes: dialysis, cardiac surgery, intervention cardiology, clinical chemistry, dental surgery, geriatrics, gynaecology, hospital pharmacy and orthopaedics. The hospital has the largest ER department in the Netherlands. Also offers ambulatory and emergency care on all specialties.

#### **Key figures for Amphia Ziekenhuis**

- 3 locations
- 100 outpatient departments and 50 clinical departments
- 950 beds
- 244,000 care days; 55,100 day admissions; 45,100 long stay admissions
- 33,500 surgical interventions
- 833,000 outpatient visits
- 4800 employees (300 physicians and 300 volunteers)

#### **Project: Epic at Amphia**

In 2009 the hospital started a procurement process for a new EHR system. The objective was to become more efficient by procuring an integrated EHR, from patient registration up and through billing that could support care pathways and support the harmonization of work processes in and between the three hospital locations. The main drivers for procuring a new suite solution were:

- Reuse data: Sharing information between departments and all three hospital locations
- Integrated EHR: register information once!
- Support work processes through standardized care pathways

The hospital has invested 27 million Euros over 4 years in the project. Thus, far the project has remained within scope and budget. Due to removal of paper processes, staff has been reduced with 58 people. Today many work flows are harmonized and the whole hospital use a shared database. For the management, the installation of the EHR system is seen as building the hospital brand, showing their commitment to continuous work on modernizing the organization and improving quality.

#### **Needs assessment and user involvement**

Physicians and nurses took part in the selection process. They did not write a detailed RFP /specification. Instead, during workshops they identified the most important needs in the different professional groupings. That was very useful for the organization, because they managed to articulate the many different needs and requirements, and thus to highlight the need for prioritization. This gave the project a strong identity among the staff. In particular, the consensus process leading up to the choice of clinical guidelines was experienced as tough. A solution had to be found that should be accepted by professional groupings and adhere to national recommendations. It is recognized by the hospital management that the implementation of a system supporting standardized clinical pathways needs to be discussed up-front with hospital staff. In order to succeed with such organizational change, everyone needs to contribute. That means that they will need commitment and understanding throughout the entire hospital.

Except from test coordinator and project managers, the program was staffed by using the hospitals own resources. As a result, the hospital could build and maintain important knowledge in house. When choosing a vendor the hospital focused on:

- The system should be a proven product
- (long-termed) Implementation support (including user support, and peer collaboration after implementation).
- The system could support organizational change process
- The business case (cost/benefit analysis)

#### **Technical solution**

The EHR system uses Dutch and international standards, DBC, DHD/ICD10, Medication G-standard, chargeable, IHE, HL7.

#### **Functionality and experiences with use**

With regard to implementation, the decision was made to go live in all three hospitals at once. An interdisciplinary and cross-departmental kernel-team of 250 super users was established, both nurses and doctors. The team received full EPIC training and had regular meetings throughout implementation. The team did workflow analyses, configuration, education and support, they act as test bed for new functionalities.

Before installing the EHR system, the hospital was primarily a paper based organization. The system conversion was experienced as strenuous, with abundance of manual scanning of charts.

During implementation the hospital experienced that the nurses easily adapted to the system. The implementation was more challenging for the medical doctors. They were reluctant to change existing work process and did not want to give up their paper records. They lacked capacity to train themselves in the use of a new, advanced system. Some friction also stemmed from the fact that the vendor did not want to integrate with existing systems, but instead use or develop proprietary solutions, for some specialists it was problematic not to be able to continue using a specialist system/functionality tightly integrated with existing work routines.

The EHR system supports the documentation needs of all specialists, apart from ear-nose-throat doctors. Throughout the first phase of implementation ("Migration" 2009-2011) the hospital has gotten:

### **Care processes**

- Electronic record: overview, ordering, results, DBC's, letters
- Emergency department

### **Patient Logistics**

- Patient registration
- Appointment scheduling not in use
- Admission, discharge and capacity management
- OR: scheduling, patient tracking, event registration, OR notes
- They are not utilizing reporting yet and there is no integration with (human) resource planning

### **Care administration**

- DBC-validation and handling
- Uses Epic administration and billing modules. Co-developed Dutch billing module with 6 Epic developers. DBC Dutch billing standard
- Management information
- Information technology
- Workplace: workstations, printers, single sign-on
- Infrastructure
- Interfaces
- Conversions

In phase 2 of implementation ("Documentation and medications" 2013) the focus will shift from the digitization of paper records and processes and on to organizational changes according to pathways and optimizing work processes, especially processes between the locations will be standardized. Some simple pathways will be realized.

In phase 3 ("Specific modules" 2014) My Chart for patients and EpicCare Link (a Web user interface for the EHR systems of cooperating GPs) will be implemented. The aim is to be able to shift more work on to GP and patient, eg. checking medication lists. The implementation of more complex pathways is planned to occur in a third and final phase.

A hospital doctor sharing his experience with the new EHR system highlights that it has been a strenuous process, but that they have accomplished much in a short time. Throughout the last three years their ambition has been to move from HIMSS stage 2 to 6. Both the mobile terminals and the log-on process with identity card are experienced as easy to use and efficient. For him, what is most beneficial is the gathering of having all information available at one place, and to be able to access information from other personnel groups. The main principle has been single registration, now data is being reused across the hospital. When a patient is transferred to next department, there is no need to repeat the information. The data quality also seems to be improved, more structured and accurate. However, some details are missing. Because it is slower to type on a computer than to handwrite people tend to leave out some details. Also the system offers problem lists that are very structured, however, doctors have to get used to working with it before they can get the benefit. Just the shift from paper to electronic documentation has been radical. Yet, besides from more structured documentation, they have not gotten the full potential out of the system. In his view, he would like to have the opportunity to slice and dice through the information himself. He also

emphasizes that the use of pre-developed functionalities from the vendor as helpful, for instance order sets, developed and approved by healthcare personnel.

#### 6.6.6 Digital Services for Citizens

Digital healthcare services for citizens have long been a topic for development in the Netherlands. With a multitude of actors involved in the financing, provision and monitoring of healthcare, online services for patients (eBooking, eConsultations, portals, etc) are distributed throughout a large and fragmented landscape. There are few, coordinated national initiatives, nor strategies to develop such. The e-health citizen services that are offered so far are locally developed, by single institutions, municipalities, hospitals etc. There are GPs offering e-consultations, digital appointment scheduling, but few patients are aware of the possibilities. The GPs receives some re-imburement for offering such service. There is a possibility that velocity of the citizen service development will be influenced by the insurance companies.

NCPF is concerned with the lack of integration throughout the patient trajectory and envisions a more informed and active role for the patient in the healthcare system. This requires work on building awareness through portals and websites, and development of new digital solutions that allows the patients to capture and disseminate data about their own health, to promote self-managed care. In the short run, the goal is to develop a patient health record. In the longer run, the aim is that patients shall have access to their entire medical records through a secure portal.

Medication is seen as a key driver for the development of EHR systems, from the patient point of view. According to a recent report 68 % Dutch is interested in having digital access to their medical records (chronically ill: 79 %). Having been explained the concept of a PHR, 59 % says they would use it if available.<sup>68</sup>

NCPF has published a pamphlet with a user story envisioning and visualizing the patient as an informed and active actor in the medication loop. The project is supported by the government. They are now negotiating with industry and healthcare providers to set up a PHR program to realize the vision. The aim is to describe standards by 2014, run a pilot, and implement system within 2015. The plan is to make the PHR accessible through the AORTA. The medication record should contain information about for example self-medication, side effects of medications, allergies and their will. With the patient as an active user of the medical record, he/she should be able to write a medication diary and perform quality checks on the content contributed by the healthcare professional. Important elements in a PHR would be that it is universally accessible; layperson comprehensible; user friendly; and lifelong. However, there are still many unresolved issues concerning the development of a PHR; how to transfer responsibility, how to handle digital divides, and how to filter information to avoid information and work overload for service providers.

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<sup>68</sup> Motivaction research 2012

The growth of mobile medical applications is another trend within the area of digital citizens' services. The rapid development of this area has led to a demand for regulations. In response, KNMG, together with VVAA (insurance company for healthcare professionals) are involved in a feasibility study for trademarks/CE marking for medical apps. Trademark should inform users about the medical reliability of the application and protect doctors from liability issues surrounding their use and misuse. The initiative is relevant also for other areas within health IT, such of process support and decision making support functionalities for EHR systems.

### 6.6.7 Secondary Use of Data

The AORTA infrastructure is not intended for gathering data for secondary use. Strategy since 2002 to leave information *at the source*, and build *connectivity between actors*, rather than central system building. There are currently next to none reporting of person-identifiable medical data to national registers. In general, the Dutch approach has been to avoid central storage of sensitive information. The reason is twofold. This can be understood in the light of a strict Dutch regulatory tradition on privacy issues, strongly influenced by the experiences of Jewish persecution during the 2<sup>nd</sup> world war.

## 6.7 Final Reflections

Following 15 years of technical development and policy making, why did the national EHR project fail? Key actors as NICTIZ and NIA point to the political process surrounding the introduction of AORTA rather than the conceptual choice. The national EHR was fundamentally going to change the way healthcare is practiced. The essential question was not what technical infrastructure to build, but rather what future healthcare to realize, and the role of ICT in it? By connecting to AORTA healthcare professionals and patients would take the leap from local information islands to information sharing, which could potentially support a more integrated, patient-centered form of care. However, the EHR concept also implied changes to a legal framework on privacy and information security deeply embedded in Dutch history (2<sup>nd</sup> WW) and culture (liberalism). In retrospect, it is easy to see that such sociopolitical reform required a far more extensive involvement of end users and public debate than what was actually conducted. As a result, the project failed to mobilize sufficiently political support in the final round of decision making.

Then, how do the actors evaluate the national EHR project? In retrospect, NICTIZ considers the original plan for a national EHR system to have been too ambitious, demanding substantial changes both in legal framework and the organization of work practices among healthcare personnel. Today, the AORTA infrastructure is functioning as a de-centralized solution, without central storage of information. This solution adheres to existing legal framework. Healthcare personnel continue to work in their own local EHR systems, which according to NICTIZ is preferable, as the idea of one, shared EHR system was nor preferable among professionals. The result is to be understood in the light of a de-regulated healthcare system with a highly diverse and autonomous assemblage of actors operating without strong central governance.

While the de-centralized system is considered to be safer and more suitable to the organization of Dutch healthcare, NICTIZ also sees challenges to the choice of architecture. The de-centralized solution is resource demanding due to the need to integrate a large number of very different systems. What is more, the challenge identified back in 1996 - isolated islands of information - persists. The issue of to how to support integrated care remains unresolved. Further system

development is needed in order to support communication, collaboration and coordination across the levels and actors of the healthcare system.

The market-oriented approach appears highly stimulating for local and regional innovation. Without a central, top down governance of the eHealth development the market, a diverse set of professional groupings, user organizations and private actors respond with a high variety of eHealth initiatives. NIA stands for a positive trend with regard to strong sector ownership and collaboration. AORTA is developed and holds the potential to host a range of nationally shared service applications. However, neither the hospital nor the rehabilitation clinic that we visited was familiar with neither the NIA platform nor the AORTA infrastructure. Instead, they were focused on their own local processes.

In the de-regulated healthcare system the insurance companies, as the strong financial players, have gained much power and responsibility. Currently the insurance companies are actively supporting AORTA through the NIA/ZVZV collaboration. However, the AORTA infrastructure only caters to a minimum of the ICT needs in a healthcare organization.

What will this mean for the road ahead? One possible development is that critical information is exchanged through AORTA, while each enterprise builds its own, private solution according to their functional needs. This will support the quality work within an organization, but not support the continuity of care between healthcare organizations.

Another possibility is that the insurance companies start building regional infrastructures to compete with AORTA by allowing for information sharing between hospital, GPs and care providers that they commission services from.

However, patients do not stay within enterprise walls, patients travel and move. Patients are mobile within and between the different levels, actors and disciplines of the healthcare system. Patients' needs and demands are dynamic and diverse.

And so the key questions remain, as patients move around the healthcare system, who oversees the continuity of care? Which instance makes sure the patient does not have to rely on the ethics and capacity of individual care givers to ensure information follows the patients around? What or who should be the integrative force ensuring patient-centeredness in the Dutch eHealth system? Who takes responsibility for that which does not "counts" and the equitable distribution of costs and benefits? What authority (market, state, professional) will govern the development eHealth in the direction of a healthy interplay?

## 7 England

### 7.1 Demographic Data and Political Tradition

Population (30.06.13)	53 900 000
Area (km <sup>2</sup> )	130 395
Political tradition	Constitutional monarchy and parliamentary system
Administrative levels	State, region, county, civil parish

### 7.2 Key Figures for English Healthcare System

<b>Health status</b>	
Life expectancy at birth (years)	78.6 (Men)
<b>Expenditure on health</b>	
Spending per person on health services	1.9
Spending on health services (% of total expenditure)	22
Public financing (% of total expenditure)	83
<b>Health workforce</b>	
Practicing doctors (per 100.000 population)	70
<b>Healthcare activities</b>	
Day cases (% of all hospital admissions)	41
Average length of stay, acute beds only)	4.3

Source: [UK National Audit Office 2012](#)

### 7.3 Gathering Information on the English Case

The empirical material for this chapter is gathered through:

Desktop research, May-June 2013 and January–March 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the English healthcare system, eHealth strategy, key actors and initiatives.

Study trip, October 2014: Nine participants from the Directorate of Health. The study trip was organized around the following program:

STUDY TRIP TO ENGLAND – HEALTH & CARE INFORMATION CENTER, OKTOBER 2014			
Tuesday 14.10.14	eHealth strategy; past, present and future	Jeremy Thorpe and Mark Reynolds	
	Summary Care Record	Richard Ashcroft	
Wednesday 15.10.2014	Care.data	David Ibbotson and Eve Roodhouse	
	Technical Architecture – interoperability, enterprise architecture	Shaun Fletcher	
	SPINE - demographics, conformance of local systems	Stephen Smith	
	Standards	Nicholas Oughtibridge and Keith Naylor	

On the basis of the information gathered throughout the study trip, the report was revised focusing on practical experiences with realizing policies in practice.

In this chapter we will use the empirical material to describe the past, present and future of the English eHealth system. Obviously, the description is not exhaustive. The report reflects the knowledge needs of the Norwegian One patient – One record program. When situated perspectives and viewpoints are expressed, we highlight this by referring to the source. To validate the findings, the host institution has been invited to add comments and corrections to the report.

#### ***7.4 Financing, Governing and Organizing Healthcare***

The period since 1997 up until 2010 has witnessed a series of organizational changes to the English healthcare system designed to decentralize responsibility from the Department of Health to regional and local levels.<sup>69</sup> Major reforms included the creation of Primary Care Trusts - PCTs, which are responsible for commissioning health services for geographically defined populations; the introduction of new types of NHS providers, Foundation Trusts, with greater financial and managerial autonomy; and the greater use of private-sector capacity to deliver publicly funded healthcare. At the same time the Department of Health has created a number of new semi-independent bodies to assist in setting priorities and monitoring standards for different parts of the healthcare system.

As a coalition of the Conservative party and the Liberal party took over government in 2010, an extensive investigation into healthcare was initiated focusing on the total re-organization of NHS England on the basis of blend of Conservative and Liberal Democrat ideas.<sup>70</sup> Key to this work is the Governmental White Paper [Liberating NHS: An Information Revolution NHS](#) and the knowledge assessment study which this rests upon produced by the independent [NHS Future Forum](#). The investigation pointed to challenges concerning an ageing society, rise of long term conditions and increasing expectations towards the delivery of healthcare in combination with increasing costs, limited productivity gains, and constrained public resources form the background for the ongoing reform of the English healthcare system. The following key objectives were singled out and form the basis for the largest re-organization of the NHS up until now:

- Putting the patient in the center. More information, choice, and control over your own treatment and care - «No decision about me without me».
- Ensure more time and resources for health professionals so that they can focus on producing health quality outcomes at an international top level.

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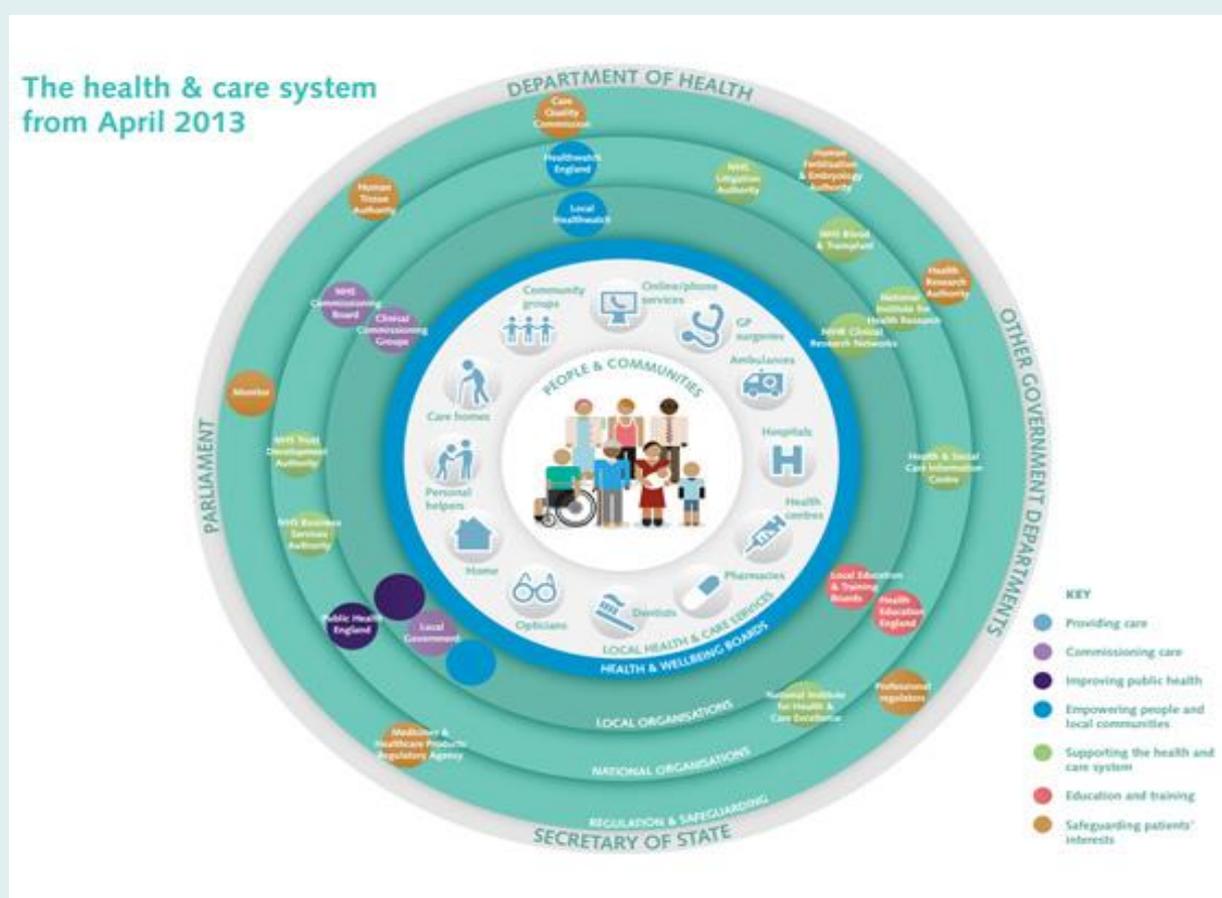
<sup>69</sup> For an extensive introduction to the English healthcare system up until 2010, please see: [http://www.euro.who.int/\\_data/assets/pdf\\_file/0004/135148/e94836.pdf?ua=1](http://www.euro.who.int/_data/assets/pdf_file/0004/135148/e94836.pdf?ua=1)

<sup>70</sup> An important background for the investigation was the recent learnings stemming from an inquiry into a series of maltreatment cases, and deaths from treatment at Mid Staffordshire NHS Foundation Trust (also known as the [Sir Francis report](#)) revealed serious quality breaches in the healthcare system The report became an important argument for the liberal reform of the healthcare system.

- Less national governance and more autonomy and more responsibility to the employees of NHS and the service providers for developing services according to patients needs and aspiration
- Reduce bureaucracy and increase efficiency by reinvesting in the first line of service. In line with the [Quality, Innovation, Productivity and Prevention Agenda](#).
- Focus on quality measurement and monitoring of service provision to promote competition and innovation

The starting point for the reform was the Health and Social Care Act of 2012, which came into being on 2013. The act effects who makes decisions about NHS services, how these services are commissioned and the way money is spent.<sup>71</sup> In the following we take a closer look at the emergence of a newly liberated English healthcare system.

Figure 22. English Healthcare System



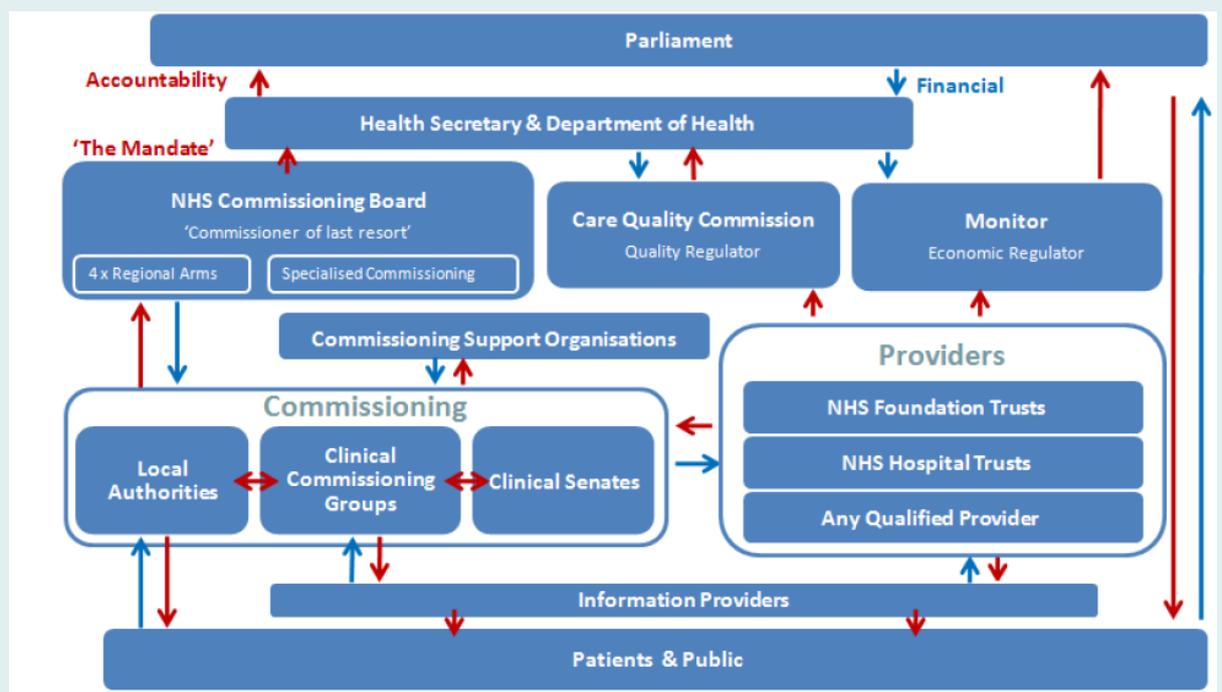
Source: NHS England

<sup>71</sup> <http://www.england.nhs.uk/wp-content/uploads/2014/06/simple-nhs-guide.pdf>;  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/194002/9421-2900878-TSO-NHS\\_Guide\\_to\\_Healthcare\\_WEB.PDF](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/194002/9421-2900878-TSO-NHS_Guide_to_Healthcare_WEB.PDF)

Healthcare services are universally available free of charge to patients in England. Only 8 % of consumed services are private, and then primarily delivered on top of the public service financed through private insurance.

Healthcare in England is funded by taxation with a fixed budget available to spend on services for the whole population. Nearly half (47 %) of the NHS budget is spent on acute and emergency care. General practice, community care, mental health and prescribing each account for around 10 % of the total spend.

Figure 23. NHS Structure: Accountability and Financial Relationships



Source: HSCIC

[The Secretary of State for Health](#) has ultimate responsibility for the provision of a comprehensive health service in England, and ensuring the whole system works together to respond to the priorities.

[The Department of Health \(DH\)](#) provides strategic leadership for public health, health and social care systems. It does not manage NHS, but commissions NHS through a yearly refreshed which sets out the ambitions and directions for NHS England, for which it will be held to account by the Secretary of State for Health.

[NHS England](#) is a political independent body, at arm's length to the government.

- provides national leadership for improving outcomes and driving up the quality of care
- oversees the operation of clinical commissioning groups
- allocates and accounts for resources to clinical commissioning groups
- commissions primary care and specialist services

[Public Health England](#) is an executive agency of the Department of Health and provides national leadership and expert services to support public health, and also works with local government and the NHS to respond to emergencies, and address health inequalities.

[The Care Quality Commission \(CQC\)](#) regulates all health and adult social care services in England, including those provided by the NHS, local authorities, private companies and voluntary organizations.

[Monitor](#) is established as a regulator to protect the interests of patients following liberalization of service provision. Monitor has responsibility for national pricing and tariff and helps commissioners ensure that local services continue if a provider is unable to continue providing services.

[Healthwatch](#) is a new organization (national and local level) and functions as an independent consumer champion, gathering and representing the views of the public about health and social care services in England.

[The National Institute for Health and Care Excellence \(NICE\)](#) develops guidance and set quality standards for social care.

In addition, following the reform, local authorities have taken on a bigger role, assuming responsibility for budgets for public health, to encourage integrated working between commissioners of services across health, social care, public health and children's services.

NHS England has a budget of about £95 billion. Planning and purchasing healthcare services was previously performed by England's 152 primary care trusts. The 2012 Act replaced the PCTs with 211 clinical commissioning groups (CCGs) led by clinicians which now are responsible for £65 billion of the NHS budget. The aim was to separate the political from the operative.

The CCGs are responsible for assessing the reasonable needs of their populations and using their buying power as purchasers to secure services that are affordable and of the highest quality. Each CCG serves a median population size of around 250,000 people (range 61,000 to 860,000). CCG budgets are allocated on a 'weighted capitation' basis. This means that budgets are set based on the size of the population, and adjusted for factors like the age profile, health, and the location of the population. The rationale behind the new system is that CCGs are clinically led local organizations that know the area in which they are working, and so are able to commission services that are specifically required by the population that they serve.

Aiming to give greater choice and control to patients in choosing their care, the Healthcare Act opens for competition for NHS funding. CCGs can commission any service provider that meets NHS standards and costs. These can be NHS hospitals, social enterprises, charities, or private sector providers. However, service providers must be licensed by the Monitor and take into account both [National Institute for Health and Care Excellence \(NICE\)](#) guidelines and the [Care Quality Commission's](#)

(CQC) data about service providers to be able to legally provide services.<sup>72</sup> The English Healthcare system is now moving away from a 'Payment by Results model' introduced in 2003<sup>73</sup>, towards a payment system based on quality of care and health outcomes achieved.<sup>74</sup>

Highly specialist services and primary care is commissioned by NHS England. The CCGs employs the GPs and other health professionals, such as nurses. GPs are mainly private practices. The trend is a move away from single GPs, towards GP offices. The GPs function as gatekeepers to specialist services. In addition, the CCGs commission most services, including:

- planned hospital care
- rehabilitative care
- urgent and emergency care (including out-of-hours)
- most community health services
- mental health and learning disability services

Figure 24. Differences between NHS Foundations and NHS Trusts

Differences between NHS foundation and NHS trusts		
	NHS foundation trust	NHS trust
<b>Government involvement</b>	Not directed by government, therefore more freedom to make strategic decisions	Directed by government
<b>Regulation:</b> <b>Financial</b>	Monitor	Trust Development Authority
<b>Quality</b>	CQC	CQC
<b>Finance</b>	Free to make their own financial decisions according to an agreed framework set out in law and by regulators. Can retain and reinvest surpluses	Financially accountable to government

<sup>72</sup> To get a license, providers will need to meet essential standards of quality and safety. They'll also have to follow certain behaviors relating to price setting, integrated care and competition. More importantly, providers will have to ensure services don't stop in the event of financial difficulties. If a provider does not fulfil the terms and conditions of the license, both Monitor and CQC can take independent action, such as issuing warning notices or financial penalties.

<sup>73</sup> An activity based system that reimburses providers for the work that they carry out, at an agreed national price counts for 30 % of NHS expenditure, the rest is covered by block contracts and local variations on these.

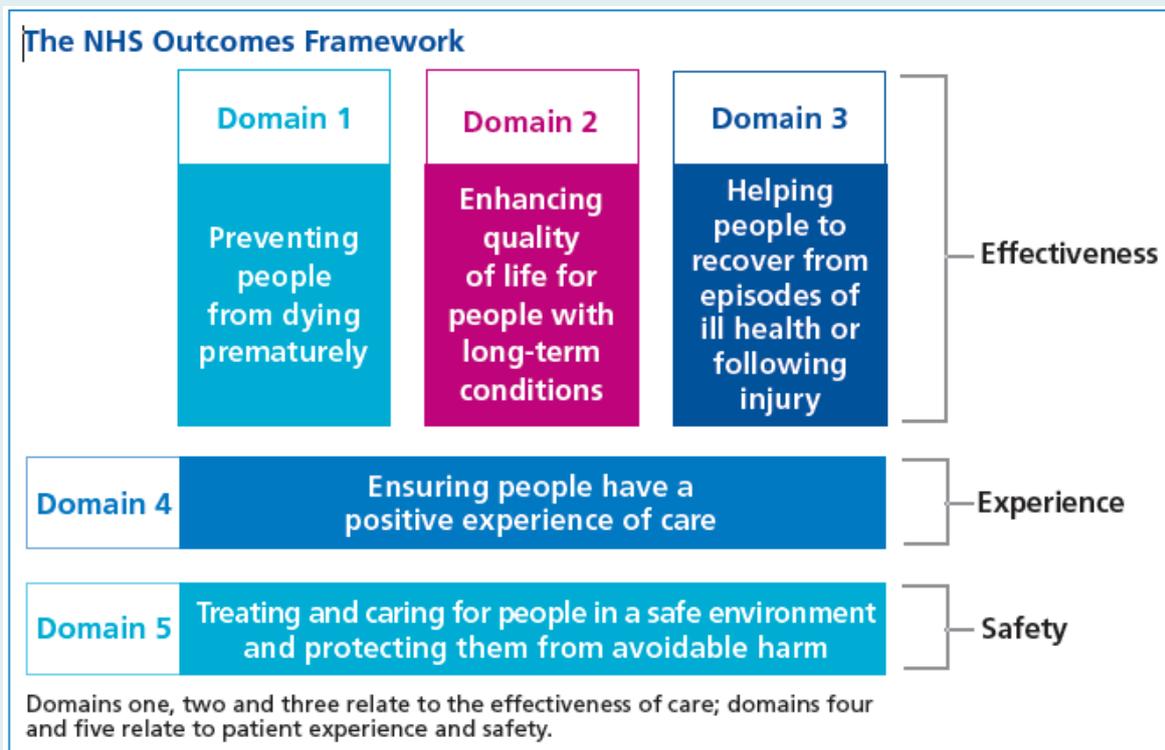
<sup>74</sup> Key here is outcome measurements. Rather than measure healthcare processes, for example – the number of hip replacements performed – it is better to ask patients whether their hip replacement was effective. This measures how good hip replacements are from a patient perspective. By using this measure, providers of hip replacements should focus on providing a good hip replacement service to patients, as opposed to focusing mainly on the number of operations completed.

The majority of NHS services, such as hospitals, belong to either an NHS trust or NHS foundation trust. It is the Government's ambition that all NHS trusts will ultimately become NHS foundation trusts (see figure 23). Each trust can have multiple sites, meaning one or more hospitals often belong to a single trust. In NHS foundation trusts, the board of directors is directly accountable to their local population through their membership and council of governors.

HSCIC points out that the hybridity of the healthcare system is challenging. The result of liberalizing the system is high degree of fragmentation at certain levels. There is no *one* actor with responsibility for the coherence of the system. Instead, quality has become the organizing principle of the NHS and the potential integrative driver. Quality is defined as excellence in patient safety, clinical effectiveness and patient experience. The underlying principles that define quality of care have been defined in the NHS Outcomes Framework (see figure 24). No individual or organization is offering high-quality care unless they satisfy all of these principles.

The NHS outcome framework provides a process by which performance is measured, and acts as a catalyst to drive quality improvement. The framework was developed in partnership with clinicians and stakeholders. The framework sets out outcomes and corresponding indicators that the Department of Health uses to control the operations of the NHS. The framework is also used by the CCGs to measure the results of the service providers.

Figure 25. The NHS Outcome Framework



Patients have a free choice of hospital. A trend towards more specialization in the hospital sector is expected to drive patient mobility. Especially the waiting time scenario seems to be an important factor for patient mobility. That, again, generates a demand for ICT systems that can support this complex ecosystem by enabling integrated care for patients, and governance through quality measuring for the Government. In the English healthcare system, ICT is seen as a key enabler for:

- Increasing quality of treatment and care
- Increasing health benefits and trust in the healthcare system
- Contributing to the empowerment of service users and realizing shared decision making

### ***7.5 English eHealth: Past, Present and Future***

While in England, citizens have a legal right to access their health information, this has proven hard to realize in practice. There is no coherent health record in place and paper versions exist next to digital records. The existence of many different systems, with a diversity of data structures and definitions in use, make it hard to construct a coherent overview of patient trajectories.

In order to make a change, in 2009 a major health IT program was introduced – The National Program for IT (NPfIT). According to the NHS, NPfIT was the world’s biggest civil information technology program. Following ongoing problems surrounding scope, planning, budgeting and lack of benefit realization, the program was dismantled by the Conservative-Liberal Democratic Government in 2011. Since then, the strategy for eHealth has changed fundamentally from a centralist to a localist approach in which minimal state intervention and local innovation is key.

According to the HSCIC, the setbacks of the NPfIT, along with a series of failure of safety and privacy routines, had led to low level of trust for ICT among patients and professionals in England. Current eHealth strategy is not so much about technology, as about restoring trust and facilitating a cultural change in which information handling and sharing is seen by patients and professionals as a natural ingredient of healthcare practices.

In the following we give an overview of the history of English eHealth and how the remains of the NPfIT are being further developed and used to realize the current vision for English eHealth.

#### ***Timeline***

**2002:** Based on a report on the low governmental spending in health IT and a political ambition to bring NHS England into the 21<sup>st</sup> Century,<sup>75</sup> the Blair Government launches the [National Programme](#)

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<sup>75</sup> A review of long term trends in the NHS had been published in April 2002: ‘Securing our Future Health: Taking a Long-Term View’ (the Wanless Review). The interim Wanless Review, released in November 2001, had already highlighted the low investment in information technology in UK healthcare (1.5 per cent of NHS spending), both in comparison to other UK industry sectors and other countries’ health ICT spending. Alongside the Prime Minister’s 2000 commitment to increase NHS spending overall over six years, in order to bring spending up to the European average as a proportion of GDP, the Wanless Review helped pave the way for the Chancellor of the Exchequer, Gordon Brown, to approve the funding of NPfIT, a program which had already received the Prime Minister’s seal of approval. While this meant that funding was not an issue for the program, it instead created a different problem: a lack of detailed cost-benefit analysis which normally would have been

[for IT](#) (NPfIT). The main objective is to digitize medical records and move the NHS towards a single, centrally mandated EHR system that enable connection between 3000 GP practices and 300 hospitals, providing secure and audited access to these records by authorized healthcare professionals. The program would be financed nationally and organized around five regional hubs with each their record system<sup>76</sup> in addition to one central unit. Competition was announced for the central system at the national level and for each and one of the regional systems according to a similar specification. Main components and services were:

- **NHS Integrated Care Record Service:** Consolidation around five regional EHR systems that would give patients and professionals interactive access to complete medical records 24/7.
- **New National Network (N3):** Broadband network connecting all NHS locations and 1.3 million employees across England.<sup>77</sup>
- **Choose and Book:** A national electronic referral service which gives patients a choice of place, date and time for their first outpatient appointment in a hospital or clinic.
- **Picture Archiving and Communication System (PACS):** national support for the delivery of digital x-rays and scans technology to NHS trusts in England.
- **ePrescription.** Enabling electronic prescriptions to be generated, transmitted and received so that pharmacists and other dispensers can dispense against them.
- **NHS mail** a directory service and secure messaging for all NHS providers.
- **SPINE:** A communication platform for national applications, services and directories that support the exchange of information across national and local NHS systems.

**2003:** Contracts for SPINE and the five Clusters were awarded. For each cluster a different Local Service Provider (LSP) was contracted to be responsible for local service delivery. This structure was intended to avoid the risk of committing to one supplier which might then not deliver, as well as to introduce an element of competition. Three national<sup>78</sup> and four regional<sup>79</sup> service providers were signed on to contracts for more than £6 billion.

**2005:** [NHS Connecting for Health](#) is established and given the responsibility for implementing the NPfIT and operating NHS IT functions.

**2009:** NPfIT is met with massive critique from several groupings, and cannot meet deadlines while also struggling with large budget overruns. In particular the clinical and the patient administrative

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required to justify program expenditure on this scale. At the same time, the Parliamentary Under-Secretary of State for Health, Lord Hunt, announced the proposed major IT reform to the NHS on 12 June 2002, along with the publication of the Department of Health's 'Delivering 21st Century IT support for the NHS – National Strategic Programme' (the NSP Plan). The NSP Plan initiated what would subsequently become known as NPfIT, with its vision of “connect[ing] delivery of the NHS Plan with the capabilities of modern information technologies”

<sup>76</sup> Southern, London, East & East Midlands, North West & West Midlands, and North East.

<sup>77</sup> <http://www.n3.nhs.uk/>

<sup>78</sup> BT for N3 and central EHR solution, Atos Origin for booking, and Cable&Wireless for national catalogue services and email.

<sup>79</sup> Accenture, CSC Alliance, Fujitsu and Capital Care Alliance.

systems are challenging. Vendors retract or are being replaced. Challenges with roll out and migration of existing data was considerably underestimated. Main critical points were:

- Rushing to reap the rewards of the program, politicians and program managers rushed into policy-making, procurement and implementation processes that allowed little time for consultation with key stakeholders and failed to deal with confidentiality concerns.
- Tight central governance with lack of clinical involvement in the specification processes led to delays and lack of development, which meant no benefit realization in the core operation.
- Unrealistic ambition and imprecise demand specifications due to lacking assessment of the scale and complexity of the program was a considerable cause of delays and budget overruns.
- An aggressive timeline and adversarial contracts with much pressure and little flexibility from the buyer when problems of delivery started occurring led vendors into a difficult situation. Payment was only issued when products were ready delivered, meanwhile vendors started to experience huge financial problems.<sup>80</sup>
- Changes in the system portfolio and replacement of subcontractors led to negative effects. System development in India and USA increased the distance to local conditions and users, not the least with regards to terminology and understanding of the workings of the British healthcare system.
- No incentive system in place for enterprises to invest in standardization and implementation
- Major budget overruns. NPfIT was originally thought to cost £2.3 billion over three years. In 2006, the National Audit Office estimates the total cost of the NPfIT to be £12.4bn over 10 years, while noting that the financial value of the benefits exceeds the cost of the Program.<sup>[22]</sup>
- NPfIT lacked clear direction, project management and an exit strategy, meaning that the inevitable setbacks of pursuing such an ambitious program quickly turned into system-wide failures. Furthermore, the culture within the Department of Health and government in general was not conducive to swift identification and rectification of strategic or technical errors.

**2011:** NPfIT is cancelled. Most spending is proceeded with the new Government seeking for local software solutions rather than a single, nationally imposed system.

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<sup>80</sup> Program Director, Granger was instrumental in taking an innovative (for the public sector) approach to all of these contracts, which was the adoption of “a service-oriented contracting strategy, whereby suppliers receive payment only after the systems they have developed are taken up by users, and the services they provide yield measurable benefits within the NHS” (QinetiQ, 2005, p.2). Granger’s subsequent willingness to directly challenge contractors in relation to program delays and non-delivery was defined by his likening the management of contractors to running a team of huskies: When one of the dogs goes lame, it is shot. It is then chopped up and fed to the other dogs. The survivors work harder, not only because they have had a meal, but also because they have seen what will happen should they themselves go lame (Granger, cited in Bacon & Hope, 2013, p.121) This ‘take no prisoners’ approach won Granger critics as well as admirers, and likely contributed to problems related to a culture of groupthink and intolerance for dissent in the Department, as well as unrealistic timelines and disputes with the suppliers (Collins interview, 2014).

**2012:** Following an extensive investigation into failure of the NPfIT<sup>81</sup>, the Department of Health launches the 10-years strategy plan [The Power of Information: Putting all of us in control of the health and care information we need](#). The plan covers health, public health and social care and envisions an information system built on innovative and integrated solutions and **local decision-making within a framework of national standards** which ensures safe and secure interoperability to support integrated care across the entire health and social care sector.

Technology is re-conceptualized, shifting focus from technology and IT system to the potential for better **use of information and information management** in the healthcare system. Information in itself is seen as a source of good health:

*Information for patients and service users is an integral part of care. Like medicine, good information can heal but poor handling of information can harm.*

The actors in the healthcare sector should realize that the health record in a fundamental way is about citizens – and that it therefore **should be normal for citizens to access their health data**. The plan is to provide the support people need to navigate and comprehend available information in a manner that makes it transformable in measured health outcomes to **reduce health differences**.

The vision is an information-led culture of transparency where access to high-quality, evidence-based information about services and the quality of care held by Government and health and care services is openly and easily available. All health and care professionals must take responsibility for recording, sharing and using information to improve care. EHR systems should become the source for core information used to improve care and services, and to inform research. Information should be registered once, at point of care to reduce bureaucratic data collections and enable quality measuring.

While the strategy names a few first steps towards the realization of a coherent information system, the Government will explicitly refrain from detailed plans for building new, large IT-systems. The Government limits its role to building a minimal infrastructure, pointing to «best practice»,<sup>82</sup> and facilitating partnerships.

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<sup>81</sup> The new eHealth strategy is also positioned in relationship to the [EU Digital Agenda for Europe 2010-2020](#) and the English health and care political strategy [Healthy Lives Healthy People: Our strategy for public health in England](#) in which benefit realization in ICT projects is seen in relation to a health and care system that takes use of evidence based knowledge and assessment, and which supports innovative approach to change management in the society as a whole. Another key reference is the initiative leading up to legal changes in the care sector; [Caring for our Future](#). Also the industry is invited to prepare the new Strategy. *Intellect*, the English industry organization for technology firms delivered the report; [Health and Care Information Strategy: proposals from the information technology industry](#). Finally, an *Impact Assessment Report* was developed prior to the strategy paper, in which costs and benefits for different key actors were identified.

<sup>82</sup> Each chapter in the strategy document is supported with references to examples illustrating how different strategic objectives are realized in practice at a local level. Examples from the field of practice are also made available online in a «[case study bank](#)».

The new strategy marks a shift towards a «localist approach». Investment responsibility is increasingly becoming a local issue. Organizations can freely choose systems as long as these are interoperable. Recognizing how ICT is rapidly evolving, the strategy promotes flexibility, local innovation and a market driven development of eHealth. The central government should make health data accessible – while leaving it up to the market to develop applications on top of data. It is not seen as realistic that a central government body can describe solutions that will cover the needs of a highly diverse population.

**2013:** Rigging for the execution of the new eHealth Strategy, changes are made in the governance structure. [The Patients and Information Directorate](#) within the NHS Commissioning Board is given the responsibility to lead on future NHS information and IT strategy, including oversight of information standards and information governance. The Directorate starts detailing the strategy in annual action plans, the first release is [Safer Hospitals Safer Wards: achieving integrated health and care records](#) and the belonging release of the Integrated Digital Care Fund providing £230 million to support NHS trusts and Foundation trusts investments in ICT.<sup>83</sup>

[The Health and Social Care Information Centre \(HSCIC\)](#) is established and take over the work done by NHS Connecting for Health. Commissioned by the Directorate, HSCIC is responsible for collecting, transporting, storing, analysing and disseminating the nation's health and social care data. HSCIC is also responsible for building and delivering the technical systems that enable data both to be used to support individual care and to deliver better, more effective care for the community as a whole.

**2014:** Second Action plan released by the NHS Directorate for Patients and Information, [The Integrated Digital Care Fund: achieving integrated health and care records](#) investing additional £240 million in the digitization of the healthcare sector. Use of NHS identification number becomes a contractual requirement for providers of healthcare services.

NHS launches a new eHealth strategy; [Personalized Health and Care 2020](#) which emphasizes stronger national control with standards and expectation for interoperability, at the same time as national authorities will support local freedom of choice when it comes to decision making and procurement of ICT solutions as long as these adheres to nationally specified technical and disciplinary standards.

## **7.6 Current National English eHealth System**

In the following, we shall take a closer look at the constellation of national components and services, interoperability standards, and the Integrated Technology Fund managed by the Directorate for Patients and Information with the aim of supporting local innovation that enable local actors to comply to defined standards, connect to the national components and make procurements of digital care records at the local level.

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<sup>83</sup> A similar fund was set up for the care sector the same year; *The Better Care Fund* aiming to support the data sharing across health and care.

### 7.6.1 Infrastructure

The broadband network N3, the service platform SPINE, and NHS mail are the key components of the English eHealth infrastructure.

[N3](#) is a Wide Area IP Network (WAN) with 51,000 connections, 63 points of presence and employing over 12,000 km fiber. N3 provides the NHS Internet Gateway serving 1.3 million employees.

Below is an overview diagram of the N3 network, the N3 users and the other networks that connect to it. It shows N3 conceptually rather than exact connections. For instance there are many PoPs and several gateways, some of which actually connect via PoPs.

N3 is currently delivered by British Telecommunications, managed by HSCIC. As the contract period is about to run out, HSCIC is now assessing new options for future services. Further, in-house, developing and management of the infrastructure service is being considered.

The [SPINE](#) infrastructure is a collection of national applications, services and directories that support the NHS in the exchange of information across national and local NHS systems. The Spine connects clinicians, patients and local service providers throughout England to essential national services, such as ePrescription, Summary Care Record, Choose and Book, and Demographics services for 80 million people (more details below). It is mandatory for NHS organizations to connect to SPINE.

- Connects and services more than 21,000 organizations and links over 27,000 ICT systems within these organizations
- Single consistent source of demographic data for 80 million patients. Information is requested and amended more than 2.6 billion times a year
- 42 million Summary Care Records created and stored
- Records processed by the demographic batch tracing service currently runs at c.50m per month
- 1.3 billion ePrescriptions and 50 million EPS dispense notifications
- 2,500 new smartcard user registrations per week
- 77,000 GP2GP transfers a month

During 2014, the HSCIC replaced the original Spine infrastructure with a service in-house using agile development and open source technology.

[NHSmail](#) is a secure email service for the purpose of sharing patient identifiable and other sensitive information. Ca.500.000 staff uses NHSmail in England and Scotland, user numbers are growing at a rate of 10 % annual. Enables sharing of calendars, contact details of business partners and folders across NHS organizations. NHSmail can be accessed from most devices from all over the world.

## 7.6.2 Infostructure

A key message from the investigative work prior to the release of the *Power of Information* was the lack of interoperability and its impediment to patient safety, high quality and integrated care and the continuity of care was highlighted.<sup>84</sup>

The Government does not expect every actor to use the same system, as long as the different systems can share information. National standards are to be gradually introduced through a modular development and roll out, starting with standards for demographics and standards for electronic messages. In 2010, an [Interoperability Toolkit \(ITK\)](#) was developed and published to develop a set of common specifications for local systems which would allow data stored in local systems to be shared between healthcare professionals through the national components and services, while also attempting to standardize data access and provide common methods with regards to business process, data requirements and technical alignment. ITK uses open international standards and is aligned with HL7 and 'Integrating the Healthcare Enterprise' (IHE). The specifications have been developed as a result of consultation with local NHS ICT Directors and engagement with representatives of the clinical community. As an example, the Royal College was involved in specifying content of discharge letters. The resulting package is combination 95 % international, and 5 % national standards (which were needed in order to cater to national specificities in the healthcare system). ITK standards are not rectified by others than the UK. Nonetheless, specifications are open for accreditations.

A key objective for the ITK is to counterwork vendor lock-in. HSCIC has created a database over procurement cases. It is a list of implementations to use for trusts in the negotiations with vendors, both identifying which vendors have been accredited and documenting how much money other trusts have spent on similar installations.

While the ITK pilot attracted many participants, deployment and accreditation<sup>85</sup> has remained slow. In response, in 2012 the Information Sharing Challenge Fund (ISCF) was launched to award funding to local information sharing projects based on the ITK (development, adoption, deployment). The fund intended address the market failure in the early stages of standards adoption by making available a total fund of £2.2m to incentivize the adoption and deployment of the use of the ITK throughout the NHS in England.

In 2014 the HSCIS took over the responsibility for the ITK, and funding is channeled through [The Integrated Digital Care Fund](#) managed by The Directorate for Patients and Information. Despite having standards and incentive mechanisms in place, HSCIC notes that there currently is no possibility to sanction vendors that choose to ignore the ITK and the incentive attached to it. The apparent lack of strong governance mechanisms makes the current "localist" strategy fragile. However, the HSCIC is pragmatic about the situation. The priority is to digitalize locally first, and

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<sup>84</sup> [NHS Future Forum, Report on Information, page 18, January 2012] Interoperability tool kit (ITK).

<sup>85</sup> ITK Accreditation means that the system supplier has proven that a product has been developed to and tested against the ITK specifications. The HSCIC operates a national test center.

make sure operations are working smoothly at the ground level. There is no point stressing about with the areas where you do not have the mechanism of governance and control.

The harmonization of clinical pathways and linking these up with technical standardization has come quite a long way, mostly since most codes used by EHR vendors were originally developed in UK (READ). The combination of READ codes with clinical data is the foundation for what today is SNOMED CT.

### 7.6.3 Privacy, Information Security, Access Control

Access to the national eHealth systems is controlled through log in with [the personal NHS number](#) assigned to anyone registered with the NHS in England. The NHS number enables healthcare personnel to match patients with health records. Patients cannot opt-out from the demographic service, although they can mark their record as “sensitive” to prevent their contact details being viewed by all staff. The information governance controls protecting patient information include:<sup>86</sup>

- Registration and authentication processes that allow systems to identify which actions have been taken by which healthcare professional
- Role-based access controls, linked to the identity of each authorized healthcare professional, control precisely what they are able to see and do when logged on to the system
- Search controls that constrain how healthcare professionals are able to look up the details of individual patients
- Sensitive record controls that prevent local healthcare professionals from accessing PDS information when records are flagged as sensitive
- Tools for auditing who has looked at or amended PDS records and local access to these by 'privacy officers' so as to identify appropriate use

Registration Authorities (RAs) within each trust or healthcare organization will register all healthcare professionals who are allowed access to NHS Care Records Service systems. Records are kept of the following actions on the PDS:

- Tracing, retrievals and confirmation of a PDS record
- Updates
- Creation of PDS records (including allocation of NHS Numbers)
- Merges of demographics records

In collaboration with the healthcare sector, HSCIC has developed a [code of conduct for handling Personal Confidential Data](#).

### 7.6.4 Shared eHealth Components and Services

As mentioned above, the NHS Directorate for Patients and Information is responsible for detailing the *Power of Information* Strategy. The strategy positions the digital healthcare record as the nucleus

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<sup>86</sup> For further information please visit the [Registration Authority](#) webpage.

of a patient-centered and integrated healthcare system. Patients should have secure digital access to the record, including letters, test results, individual care plans, and needs assessments.

[Demographics Service \(PDS\)](#) is a national authoritative source of patient demographics data details such as name, address, date of birth and NHS Number for the whole of the NHS. Information on the PDS is held nationally and accessed by authorized healthcare professionals through their organization's local system.

[The Summary Care Record \(SCR\)](#) collects key clinical information, such as allergies and adverse reactions to medicines, from GPs and makes it available centrally to staff treating patients in an emergency or out-of-hours. There are currently plans to also collect information from other care settings and make it available for both primary and secondary uses. As with the SPINE, the SCR used to be out-sourced, but is today managed in-house by the HSCIC.

[Choose and book](#) is a national electronic referral service which gives patients a choice of place, date and time for their first outpatient appointment in a hospital or clinic. The system supports the patients' legal right to choose a hospital provider in England offering a suitable treatment that meets NHS standards and costs.

[The Picture Archiving and Communications System \(PACS\)](#) has been rolled out nationally and the technology is widely in use, central contracts are being ended and systems transition to local ownership.

[ePrescription](#) enables prescribers - such as GPs and practice nurses - to send prescriptions electronically to a dispenser (such as a pharmacy) of the patient's choice. While 97 % of the pharmacies have installed the system, uptake among GP practices is only 42 % (2014).

### 7.6.5 EHR landscape

While EMR systems in the GP sector is centrally funded and contracted, the hospital sector is free to choose technology. In the GP sector, coverage is up to 100%, however, NHS providers in the hospitals and other settings are at different stages of digital maturity.

[GP Systems of Choice \(GPSoC\)](#) provides a contractual framework, managed by HSCIC, to supply IT systems/services to GP practices and associated organizations in England. Prior to the setup of the HSCIC the GPs had already made a list of collaborative demands and user specifications. From that a roadmap has been constructed, and a license fee is paid to vendors who update accordingly. The GP practices are reportedly pleased with the consolidation, however – and according to the HSCIC, while no one wants to go back to earlier days, when many clinicians designed their own system feature, clinicians miss the opportunity to experiment and develop their own features instead of having to go through the more rigid process of negotiation with vendors. HSCIC are working to push the vendors to open their user interfaces for more and richer customization.

[GP2GP](#) uses HL7 standards and enables patients' electronic records to be transferred directly and securely between GP practices. It improves patient care as GPs will usually have full and detailed medical records available to them for a new patient's first consultation. This is especially important for the English citizen's, as the healthcare system allows for walk-in consultations with other GPs than your assigned family doctor.

In the hospital sector regionalization is the trend. Large international vendors, such as Cerner and Epic, are competing for contracts with university hospitals, putting them in the center of the development, before including smaller hospitals and GPs as satellites. As an example London, with its 10 million inhabitants, has consolidated on Cerner, while Cambridge, considerably smaller in geographical terms, but the more prestigious as a clinical milieu, is consolidating on Epic.

In the light of this fragmented EHR landscape, the question arise, how does central government work to secure integrated care?

In the 2013 action plan [Safer Hospitals Safer Wards](#) the NHS Directorate of Patients and Information details out the Policy strategy for eHealth. The overall vision is for a fully integrated digital patient record across all care settings by 2018 and to give citizens' digital access to their record by 2015. The key enabler will be the £260 million Safer Hospitals, Safer Wards Technology Fund. From the application criteria the following principles can be deducted:

- A confirmation of the expectation that local organizations and partnerships are best placed to make the key investments decisions that add capability in information technology in line with local context, operational and strategic imperatives as long as they meet national standards in key areas such as data security and interoperability with other systems.
- An emphasis on putting clinicians at the heart of the decision making and implementation processes.
- The core architectural principles and information standards that should be universally adopted regardless of alternative roadmaps different care communities follow to deliver integrated digital care record. First is that all providers use the NHS number as primary identifier.
- An outline of the procurement alternatives that exist to enable local economies to invest in appropriate capability and infrastructure at low cost and appropriate speed.

In order to monitor the development of EHR deployment throughout the sector, the concept of a clinical digital maturity index is introduced. The index will help local economies benchmark their capability to deliver "meaningful use" of integrated care records. The index sill further support the Government in monitoring whether the national development accords with the policy objectives detailed in the Action plan.<sup>87</sup>

Key areas for the 2013 Action plan are:

- Architecture and Standards with key technical considerations including among other things a focus on the NHS number, open APIs, Patient's access to data, and a list of national semantic, content, and trafficking standards vendors and providers are expected to comply with.
- ePrescription

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<sup>87</sup> EHI Intelligence has developed a new baseline analytical model to measure what clinical and administrative systems the 156 English NHS acute trusts have in place currently. For more information see: <http://www.ehi.co.uk/ehi-intelligence/CDMI-report.cfm>

- The Fund also gives direct support from NHS England for projects to do with implementing NHS Vista, Open Source solutions and SCR.
- Support sourcing from the marketplace by encouraging and enabling new partnership standards for the industry and the third sector by developing online resources that enable entrepreneurs to advertise their capabilities and NHS providers their needs as the basis for sustainable partnerships. As part of this a procurement toolkit is developed.
- Leadership, change management and technology skills

Key areas for the 2014 action plan are:

- ePrescription
- Development, implementation and use of Open Source software
- Technology, architecture and standards – the interoperability jigsaw:
  - Primary identifier NHS number
  - Open interfaces (APIs)
  - Open source systems
  - Interoperability standards for information sharing and transfers – ITK toolkit
- Information governance
- SCR – 36 million citizens have a record, with a requirement to upload in the 2014/2015 GP contract it is expected that by the end of 2015 more than 80 % of the population will have a SCR in place.

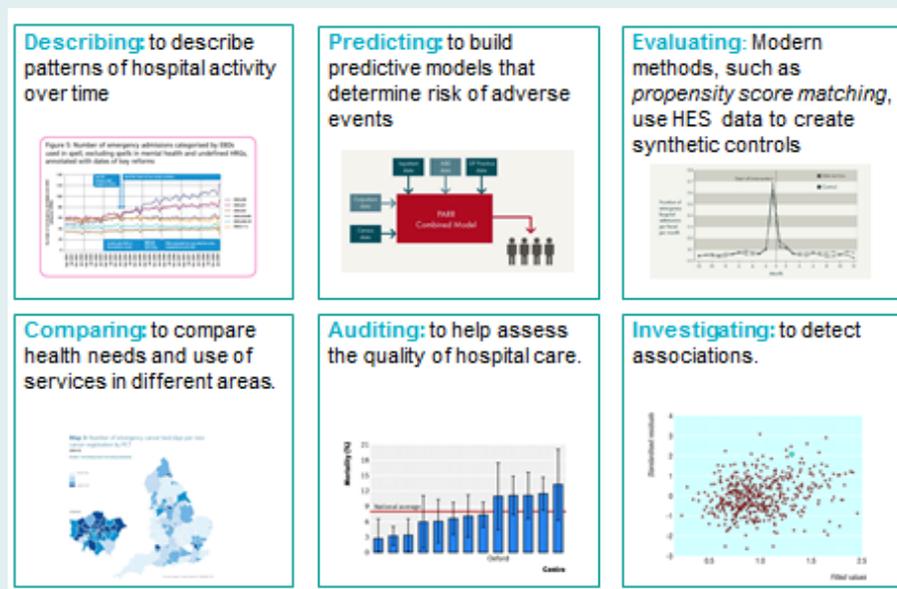
#### 7.6.6 Digital Services for Citizens

The national patient portal [NHS Choice](#) offers citizen's a broad range of health related information, including information about disease, service rights, provider directory, quality indicators, and more. In addition, the patient can use his/her NHS ID number to log in and access the service Choose and Book. The plan was for the site to give patients access to their EHR, custom made health information and treatment plans, as well as the possibility to join patient groups and forums.

Patients are encouraged to take an active consumer role in the meeting with the healthcare service, by providing feedback on the service level at the point of care. (Unknown exactly how this is thought realized in practice.)

## 7.6.7 Secondary Use of Data

Figure 26. Use of Hospital Episode Statistics



Source: HSCIC

Use of data for quality control has become a central governance tool in the reformed English healthcare system. Continuous and broad monitoring of the results of the healthcare system through data capture at all levels and open publication of results is to contribute to develop the foundation for quality improvements, policy assessment, and innovation.<sup>88</sup>

HSCIC is the central actor responsible for collecting, storing and publishing anonymized data from EHR systems, and to work on making them accessible (structured data sets, visualizations, statistics etc.) for the actors responsible for monitoring the quality of services, for planning NHS services, and for conducting research into new treatments.<sup>89</sup> The aim is to make all aspects of the healthcare systems transparent, measurable and comparable in order to enhance patient choice and stimulate competition among NHS service providers, for this a website - [NHS Choice](#) – was launched in 2013.

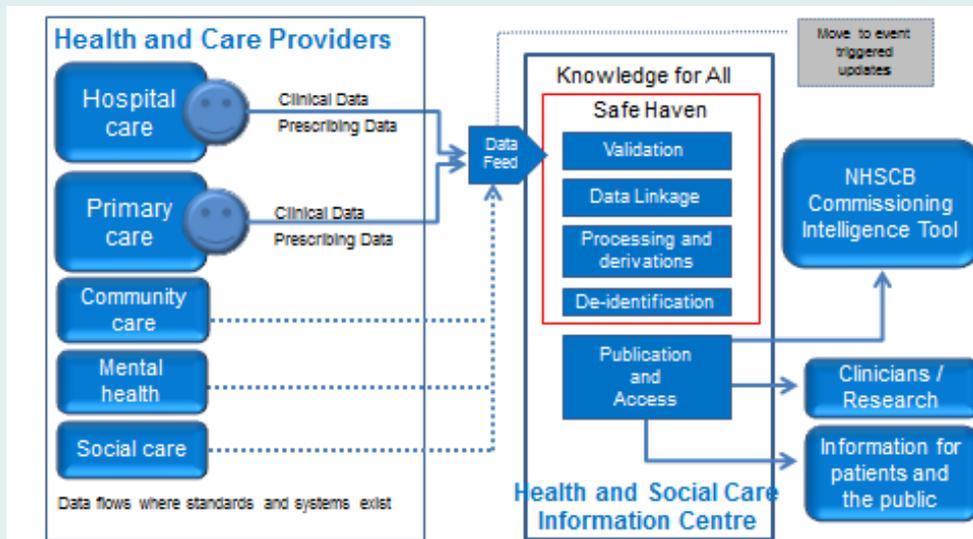
NHS has been collecting information about every hospital admission, nationwide since the 1980s. However, areas such as prescribing and test results are not currently included. What is more, primary

<sup>88</sup> The central repository is not to be used by medical staff elsewhere in the NHS giving treatment to the patient. It is meant for research, planning and monitoring purposes, for the NHS and for third parties.

<sup>89</sup> Aggregate data is made available via the HSCIC's statistical publications and reports. The data underpinning them is type 1 (as above) and, where possible, this is released as Open Data. The Data Linkage and Extract Service offers a range of products which enable customers to access type 2 and 3 data (as above). We can provide extracts from a range of individual and linked data sets and can add significant value to individual sets of data by combining and matching them at individual record level in a secure environment. Data can only be made available to those who meet the HSCIC's robust Information Governance standards to protect and control how data is managed and, where applicable, an appropriate legal basis is in place.”

sector data is not collected. As a result, it is not currently possible to see a complete picture of the care that individuals receive.<sup>90</sup>

Figure 27. Care.data Service; An Overview



Source: HSCIC

In response, NHS England commissioned a program to address these gaps. The [care.data program](#) will extend the clinical data collection from hospitals while also extract data automatically into a central repository from the EMR systems of the GPs on a monthly basis.<sup>91</sup> To secure the legal foundation for the program, a law was passed, the Health and Social Care Act 2012, which obliged them to report to the HSCIC. With it, the GPs' obligation to maintain patients' privacy under the Data Protection Act was suspended (This law also bypassed patients' consent for 'secondary use' of information collected).

Data sets could be extracted and sold for an extraction fee intended for the HSCIC to cover cost. The companies that extract the data, however, would be allowed to use it for profit-making initiatives. In the final form of the scheme, the potential users of data would be organizations within the NHS (such

<sup>90</sup> In the meeting, HCSIS emphasized the challenge for the healthcare system not to have health information throughout a patient's life, using cancer as an example. ¼ are diagnosed with cancer in an acute situation. We know little about what has happened before, whether that person has been to the GP with complaints about headache and sleepiness. With data to monitor these patient trajectories, it would be possible to design and update guidelines and screen the population. Also research would have a better source. NHS sees ownership of such data on a large English population as an asset for attracting international R&D.

<sup>91</sup> The data set excludes the 'most sensitive' data (such as HIV/AIDS status, abortions, imprisonment etc), but including rich set of clinical and biomedical data (information on family history, vaccinations, referrals for treatment, diagnoses and information about prescriptions, biological values such as a patient's blood pressure, body mass index and cholesterol levels). The written notes a GP makes during a consultation would not be extracted. The patients' name would not be included, but the NHS number, birth date, postal code, gender, ethnicity would be reported. In other words, the data would be classified as "re-identifiable".

as commissioning bodies) but also outside of the NHS, potentially (subject to approval) to pharmaceutical companies, health charities, universities, hospital trusts, think-tanks and other private companies.

The scheme was supposed to start spring 2014. However, public debate erupted around the scheme, due to the perceived risks associated with extraction of sensitive and “re-identifiable” information, the reluctance with which the NHS allowed an opt-out option, their vagueness about how the third parties access to data would be handled, and an ill-managed information campaign during January.<sup>92</sup> As a result, NHS postponed the scheme for unknown time to permit more time to build understanding of the benefits of using the information, what safeguards are in place, and how people can opt out if they choose to. HSCIC has launched an information governance initiative.

### 7.7 Final Reflections

In 2014 NHS launches the strategic framework Five Year Forward View, which partly moderates the ongoing liberalization of NHS. The framework points out that England is too large for «one size fits all» solutions, however the «let the 100 flowers bloom» strategy has not been successful either. Therefore, stronger national steering of healthcare is introduced; freedom of choice within a limited set of organizational models. New, network based work collectives combining competencies from across disciplines, levels and sectors shall enable service providers to better serve the complexity of patients’ needs.

The strategic shift is reflected in the eHealth field. The experience with the hitherto liberal strategy is that standards are not followed and the deployment of EHRs, especially in the hospital sector, and the use of the national solutions such as the summary care record and ePrescription do not proceed as fast as expected, despite the introduction of incentives. Thus, NHS launches Personalized Health and Care 2020. The new eHealth strategy emphasizes stronger national control with standards and expectation for interoperability, at the same time as national authorities will support local freedom of choice when it comes to decision making and procurement of ICT solutions as long as these adheres to nationally specified technical and disciplinary standards. About half of the efforts in the plan are brought on from the former strategy. New efforts are grouped in work streams with each its action plan to be implemented within existing organizational structures. In parallel with the strategy, a new governance- and financing model for eHealth is introduced.

The Ministry assigns an *Information Accountable Officer (IAO)* with the overall responsibility for governance model, strategic framework, regulations, investments and benefit realization. The

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<sup>92</sup><http://www.theguardian.com/technology/2014/mar/03/patient-data-inquiry-website>  
<http://ampp3d.mirror.co.uk/2014/03/03/have-millions-of-nhs-patients-hospital-records-already-been-exposed-online/>  
<http://www.theguardian.com/society/2014/mar/03/nhs-england-patient-data-google-servers>  
<http://www.informationweek.com/healthcare/electronic-health-records/feds-praise-open-data-health-cloud-launch/d/d-id/1112224>  
<http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Documents/better-information-means-better-care.pdf>

Ministry does not establish any direct steering on to its Arms Lengths Bodies (ALBs). Instead, the Ministry establishes *National Information Board (NIB)* to operate with delegated authority from the Ministry with the responsibility for defining strategy, needs and prioritization for eHealth across the healthcare system. With a strategic broad representation NIB shall ensure coordinated efforts, synergies and coherence across the healthcare system. NIB is organized with participation from all ALBs, and representatives are mandated to speak on behalf of their respective organizations. NIB shall oversee that members deliver in accordance with nationally agreed objectives and principals defined in a 5-year strategic framework developed by NIB. Members choose themselves which mechanisms to deploy in the realization of efforts. The Ministry assigns a director to manage NIB on behalf of IAO. NIB reports to IAO on a yearly basis on the results of the program, and gives advice and guidelines IAO for use of public resources. The strategy has no direct influence or decision making power for the programs financed by the ALBs themselves.

It is too early to draw any results from the new English governance model. Again, the pendulum has swung towards more national control and coordination. However, this time, there is no direct steering mechanism introduced with the new governance model. Local autonomy with regard to choice of ICT systems and use of standards remain. It is a model principally pleading to the actors will towards consensus and their ability and desire to represent their organizations interests in national negotiations and put the result into effect.

## 8 Scotland

### 8.1 Demographic Data and Political Tradition

Population (30.06.13)	5 327 700
Area (km <sup>2</sup> )	78 387
Political tradition	Devolved government within constitutional monarchy
Administrative levels	State, council

### 8.2 Key Figures for Healthcare System

#### Health status

Life expectancy at birth (years)	75.9 (Men)
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#### Expenditure on health

Spending per person on health services	2.072
Spending on health services (% of total expenditure)	20.4
Public financing (% of total expenditure)	30

#### Health workforce

Practicing doctors (per 100.000 population)	80
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#### Healthcare activities

Day cases (% of all hospital admissions)	36.4
Average length of stay, acute beds only)	5.7

Source: UK National Audit Office 2012

### 8.3 Gathering Information on the Scottish Case

The empirical material for this chapter is gathered through:

Desktop research, May-June 2013 and October 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Scottish healthcare system, eHealth strategy, key actors and initiatives.

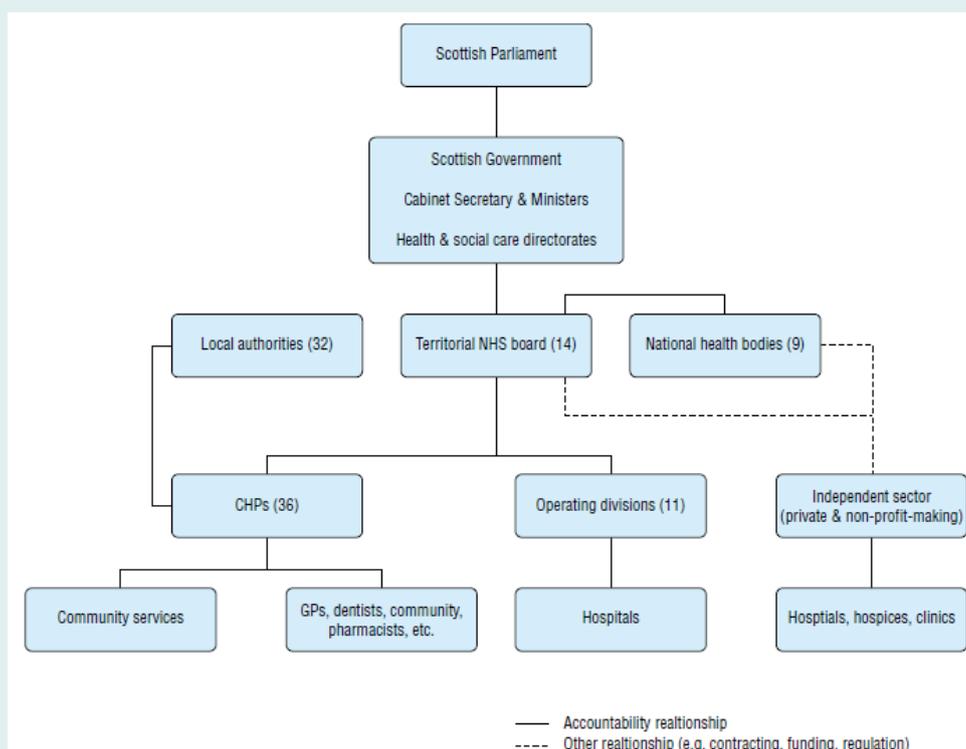
In this chapter we will use the empirical material to describe the past, present and future of the Scottish eHealth system. Obviously, the description is not exhaustive. The report reflects the knowledge needs of the Norwegian One patient – One record program. When situated perspectives and viewpoints are expressed, we highlight this by referring to the source.

### 8.4 Financing, Governing and Organizing Healthcare

Scotland is a part of the United Kingdom and comprises around 10 % of its economy. Following the process of devolution in 1999, the Scottish parliament and the Scottish government came into existence and the powers relating to devolved matters were transferred from the Secretary of State for Scotland and other UK Ministers. The Scottish Parliament has full legislative competence across devolved subjects, among which is health and social work.

Most people live in the major cities of Glasgow and Edinburgh. Population density is low in comparison to the rest of the UK due to large remote and rural areas, notably in the Highlands. While the size of the population has remained relatively stable over the last 50 years, the proportion aged 65 years and over has grown significantly and is projected to increase further.

Figure 28. The Scottish Healthcare System



Source: WHO, HIT Series

The budget for devolved matters is provided as block grants by the Treasury in London. Health is considered an important political issue, accounting for over 30 % of the Scottish national budget. Health expenditures are financed almost entirely out of general taxation and are largely free at the point of need and available to all inhabitants. There is a small independent healthcare sector, with private and non-profit organizations.

The two main actors in the Scottish healthcare system are the Scottish Government and [NHS Scotland](#) (National Health Service for Scotland). Budget, policies and strategic initiatives are set by the government, while the NHS is responsible for the delivery of healthcare, and held accountable to the Scottish Parliament. Responsibility for health and health services rests with [the Scottish Cabinet Secretary for Health, Wellbeing and Cities Strategies](#) who is accountable to the Scottish Parliament. Supported by officials in the [Health and Social Care Directorate](#), the minister sets policy and oversees delivery of services by NHS Scotland.

Following the devolution in 1999, NHS trusts were merged with boards and the purchaser-provider split introduced by the UK Government in the early 1990s was dismantled. Today, the country is divided into 14 National Healthcare Service Boards with overall responsibility for planning and delivering healthcare to their population. The focus of the boards is on strategic management and performance management. NHS boards have considerable autonomy with regard to determining the pattern of care provision according to local priorities, which means that there are significant differences in the size, role, function and governance arrangements of healthcare delivery.

NHS boards employ the staff working in hospitals and the community. They also manage, through CPHs, the contracts of independent contractors in primary care such as GPs, dentists and community pharmacists.

Primary care and specialist care is integrated in the Scottish healthcare system. Within each board, responsibility for delivery is delegated to operating divisions for acute services and to CHPs for community and primary care services. Primary care service is normally the first point of contact with the NHS. Primary care acts as “gatekeepers” in relation to specialist services. The focal point is the GP or GP practice comprising a group of GPs working together to provide a range of preventive, diagnostic and curative services. Most GPs are independent contractors. Increasingly, GPs work as part of multidisciplinary primary care team. Patients can choose to see any of the doctors in the practice and often they see whoever is available.

Specialist care is provided mainly in NHS owned hospitals. 35 Emergency care and 59 minor injuries unit is run by the NHS boards. Nine national bodies are responsible for services that are best provided by a single national organization, such as ambulance transport, information, education and training and quality improvement.

The private, third sectors and next of kin are important players in the care for elderly people and in rehabilitation and long term care. There is no unitary model for this kind of care giving, thus the pattern of service provision varies widely. Increasingly, in order to integrate health and social care, the Boards work in partnership with local authorities and the third sector, in particular through the Health and Social Care Partnerships.

#### **Healthcare reform**

- Demographic changes – need to integrate health and social care
- Focus on quality, performance management

Thirty years from now the number of people aged 65 and over is projected to rise by 59 % in Scotland. Life expectancy is improving more slowly than in the rest of the UK and elsewhere in Europe and major health inequalities still exists. Increased longevity can be expected to mean more people will be living with chronic and multiple conditions and with complex health and care needs. People with long-term conditions use the greatest proportion of Scotland’s health and care services. It is projected the increase in demand for health and social care services in thirty years’ time could be 29 %.

Important principals for the making of Scottish healthcare policies are continuation of a publicly provided service with a new focus on mutuality – involving patients and the public and NHS staff as “owners” and partners rather than just users and providers – and on quality as the driver of modernization and improvement.

In 2005, an action program was launched designed to shift the balance of care away from episodic, acute care in hospitals, increasingly through emergency admissions, to a system that emphasizes preventive medicine, support for self-care, and greater targeting of resources on those at greatest risk through anticipatory medicine. The Scottish Executive committed itself to delivering its plans “through the continuing development of the NHS as an integrated service”. The emphasis on integrating care requires multidisciplinary team work and “collaboration and co-ordination between

professionals and across organizational boundaries – a partnership approach at all levels to achieve continual improvements in quality and value for money”.

The same year, a new approach to performance management was introduced. A new delivery group was established within the Health Department to ensure a sharp focus on delivery of key priorities and targets, drawing together and strengthening the performance management function by agreeing annual local delivery plans with each board, providing systematic monitoring of performance – through what became known as the “HEAT system” - and playing a more assertive role in supporting and, where necessary, intervening.

- **Health improvement for the people of Scotland** – improving life expectancy and HLE;
- **Efficiency and governance improvements** – continually improving the efficiency and effectiveness of the NHS;
- **Access to services** – recognizing patients’ need for quicker and easier use of NHS services;
- **Treatment appropriate to individuals** – ensuring patients receives high-quality services that meet their needs.

Each objective has a number of targets and measures associated with it. Targets are measured nationally and reviewed annually with boards.

In 2007, the action plan [Better Health, Better Care](#), is published containing a series of commitments to improving healthcare in Scotland, emphasizing the need for a patient centric approach, but also focusing on key themes such as quality, safety and efficiency. In the Action Plan, eHealth is seen as a means to improve (1) the efficiency of the health service, (2) the access to health services in remote and rural areas, and (3) the timeliness of service delivery.

Launched in 2011, [The Scottish Government’s 2020 Vision](#) states that everyone in Scotland is able to live longer healthier lives at home or in a homely setting. The vision sets the strategic narrative for the delivery and development of healthcare in Scotland, including the implementation of the overarching strategy for healthcare services in Scotland, the [Healthcare Quality Strategy](#), focusing on delivering health improvement and establishing six healthcare quality outcomes:

1. Everyone gets the best start in life and is able to live a longer, healthier life.
2. People are able to live well at home or in the community.
3. Healthcare is safe for every person, every time.
4. Everyone has a positive experience of healthcare.
5. Staff feel supported and engaged.
6. The best use is made of available resources.

More recent developments have increased the emphasis placed on health and social care integration, both within NHS Scotland and with social care and other service providers. The objective is the delivery of person centered services, and implementation has been taken forward through the legal requirement for greater joint working between NHS Scotland and Local Government, manifested in the new Health and Social Care Partnerships, and enabling NHS National Services Scotland to service both parties. The Partnerships are expected to deliver revised models of care for patients with long term conditions as well as increasing management of acute patients by community staff with hospital outreach support.

It is absolutely clear that integrated services can only be delivered in the context of shared information and clear communication. Substantial work has been ongoing to enable this in the context of the recommendation from the recent review chaired by Dame Fiona Caldicott that *'the duty to share information can be as important as the duty to protect patient confidentiality. Health and social care professionals should have the confidence to share information in the best interests of their patients'*. The results of this work places a responsibility on eHealth to facilitate the required information sharing to enable successful service integration.

Last, but not least, the publication of [Scotland's Digital Future: Delivery of Public Services](#) has set out a collaborative public sector approach to ICT and a focus on the needs of citizens.

Together these documents set the strategic context for NHS Scotland and for eHealth.

### ***8.5 Scottish eHealth: Past, Present and Future***

Scotland began developing national eHealth solutions at the beginning of 2000. When the first national eHealth strategy was released in 2008, the Emergency Summary Care Record, PACS and ePharmacy had been rolled out nationally, and become the cornerstone of the national eHealth architecture.

The national eHealth system is being implemented in a decentralized manner since the eHealth strategy states that a large single database is not preferred. The Scottish government and the NHS Boards have been working collectively to deliver a more interoperable and clinically rich eHealth ecosystem covering local and national needs. The Scottish approach permits a large degree of flexibility with regard to local autonomy in choice of systems and implementation rate. According to a Gartner review, the Scottish approach compares well with similar health systems and has been delivered at a reasonable cost.<sup>93</sup>

Through the three national eHealth strategies launched thus far, Scotland has become known for its incremental and pragmatic approach to developing a national eHealth system. eHealth is understood not as a point-in-time initiative, but instead as a continuum of managed change brought about through a sequence of consistent strategies. With the introduction of the 2008 strategy, the basic principles for Scottish eHealth were introduced:

- Confidentiality safeguards are an obligation.
- A strong focus on the benefits and outcomes experienced by health and care professionals, rather than technology products, services and their suppliers.
- The approach to introducing eHealth improvements will not be via a 'large complex national IT project'. Instead the approach is incremental, making connections between existing systems and filling gaps where necessary in order to move to progressively stronger and more integrated support for provision of care.

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<sup>93</sup> <http://itsurvey.gartner.com/itsurveydocs/itkmdl3enterprisesummaryreport.pdf>

- The concept is a clinical portal presenting information to clinicians from a variety of information systems. Progressive improvement in authorized sharing of information, in line with the incremental approach shall build experience about what information clinicians find most useful in care setting.
- The cornerstone of delivering the Strategy will be a nationally coordinated approach, collaborative at all levels within the framework of the established partnership collective governance model and closely aligned to delivery priorities for NHS Scotland and planning processes in Boards and workforce development.
- Strong clinical leadership, harnessing the resource, knowledge and expertise around NHS Scotland and bringing it together in governance groups with representation from all the health boards and all health professional groups.

### **Timeline**

In the period from 2000 to 2008, the Scottish government was investing in and rolling out key foundational eHealth capabilities for the healthcare system.

**2000:** Planning for Scottish Care Information Store (SCO) begins an information repository that provides clinicians with secure access to patient information at the point of care (Patient demographics, Lab and radiology reports, treatment logs, clinical documents, ADT (admissions, discharge, transfer)). One CSI is established in each Board area. SCI Gateway is the system used for secure transmission of referrals and discharge letters.

**2001:** Pilot project for National ePharmacy system initiated, including ePrescription and a medication record. National implementation completed in 2007.

**2003:** Development of summary care record initiated as part of changes to the provision of out-of-hours services in NHS Scotland. National roll-out completed in 2006.

**2005:** National Picture Archiving and Communication System launched.

Community Health Index program initiated. CHI to be used as the single identifier to be used across all eHealth systems. Roll-out complete and use mandatory by law in 2010.

**2008:** The first [NHS Scotland National eHealth Strategy](#) is launched acknowledging that Scotland had already made some valuable investments through developments such as SCI Store, SCI Gateway and the Emergency Care Summary enabling a vital but nonetheless basic level of information sharing. But beyond these national developments many systems were, in effect, information silos within health boards. Convergence around common technologies was a major eHealth strategic ambition, with the benefits of lower costs and simplified maintenance. The vision for eHealth is support for the overall NHS Scotland goals as set out in the *Better Health - Better Care Action Plan*, exploiting the power of ICT to help ensure that patients get the right care, involving the right clinicians, at the right time, to deliver the right outcomes. The priorities for eHealth are closely aligned to the aims in the action plan.

It is pointed out that Scotland can benefit from its size to move forward more quickly, but only if it is able to make full use of the expertise that exists around NHS Scotland. A collective governance structure was established, and the roles of the Clinical Change Leadership Group (CCLG) described, which the single national clinical representation group for eHealth became. It is recognized that no

delivery model suits each and every initiative, and it is thus considered important to allow for local flexibility and innovation.

- Establish eHealth expertise through formation of collaborative networks of competence, with the aim of ensuring clinical lead on eHealth development
- Establish information governance with a focus on improving use of information, and on privacy issues
- Incremental development of a clinical portal, starting with technology and procedures to enable «single sign-on» to different sources of health information for authorized users
- Secure integration and interoperability for core systems
- Establish a fund to support eHealth improvements in primary and community care settings that will address modernization of GP systems effort in Primary care and social care
- CHI-based patient identification: replace the technology and improve the service
- Through steps 1-7 above, build the platform for an (virtual) electronic patient record

**2011:** The second eHealth strategy is launched, [NHS Scotland National eHealth strategy 2011-2017](#).

The eHealth Strategy is set in the context of *The Healthcare Quality Strategy* and introduces six strategic aims to govern eHealth developments at local, regional and national levels:

1. Enhance the availability of appropriate information for healthcare workers and the tools to use and communicate that information effectively to improve quality.
2. Support people to communicate with NHS Scotland, manage their own health and wellbeing, and to become more active participants in the care and services they receive.
3. Contribute to care integration and to support people with long-term conditions.
4. Improve the safety of people taking medicines and their effective use.
5. Provide clinical and other managers across the health and social care spectrum with the timely management information they need to inform their decisions on service quality, performance and delivery.
6. Maximize efficient working practices, minimize wasteful variation.

In addition integration of health and social care is a new, prominent issue. It is foreseen that health and social care organizations and structures will increasingly have to contend with an ageing population, increasing numbers of people with complex long term conditions, budget constraints, increasingly sophisticated (and expensive) treatments and rising expectations of what health and social care services should deliver. In this context, NHS Boards and local authorities are encouraged to work even closer together in partnership if services are to be increasingly person-centered, effective and safe. A key issue is thus the use of eHealth solutions in the support of care networks and pathways (e.g. for a specific disease) or through health and social care services that proactively seek to co-ordinate care for people across a range of different health and social care providers.

**2014:** The current strategy - [NHS Scotland eHealth Strategy 2014-2017](#) is released. The strategy maintains the aim of building a clinical portal enabling clinicians to have a seamless, single point of access to a variety of information.

The strategy reflects the changes having occurred with regard to use of online sources for health information. The quantity of clinical information recorded in NHS Scotland's systems is estimated to have more than doubled since 2011. With more clinically-focused systems now in everyday use, the

clinical richness of data is improving immensely. This creates new forms of challenges, including need for continuing investments and upgrading of infrastructure, mobile access for healthcare personnel, more consultation and developments targeting citizens and patients, renegotiations or replacement of large national contracts eg. for PACS, delivery of solutions to support the integration of health and social care, stronger national coordination and joint efforts to avoid duplications of activities, efforts and costs.

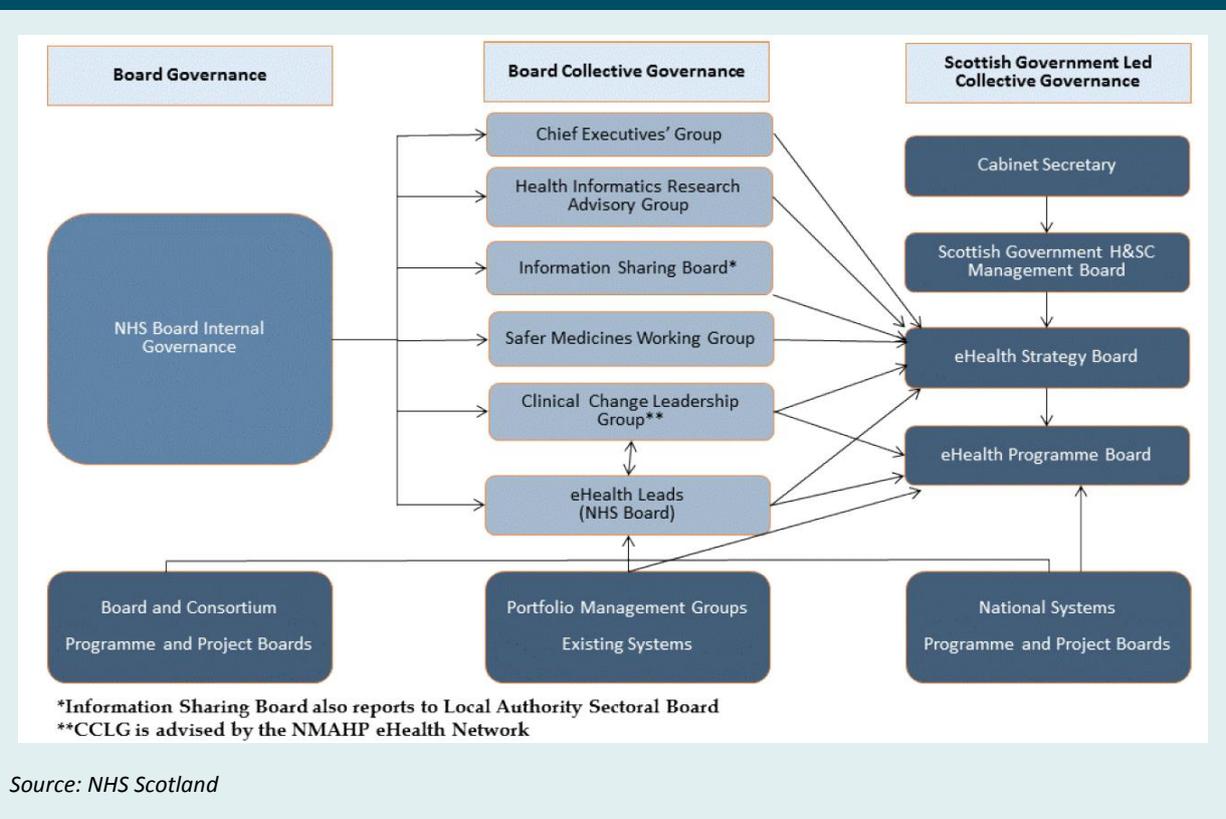
The refreshed eHealth strategy adds a seventh aim regarding innovation, to increase academic and industrial contribution to developing new and innovative solutions in health and care, and to grow Scotland’s economy in health and care technology.

### Realizing strategies

Aligning with the 2020 Health vision, the 2020 vision for eHealth is to:

- Enable information sharing and communications that facilitate integrated health and social care across all settings from the patient’s home to the hospital.
- Provide information processing, analysis and intelligence that supports and complements the work of health and social care professionals and improves the safety and quality of care.
- Support people to manage their own health and wellbeing and live longer, healthier lives at home or in a community setting.
- Contribute to a partnership between the Scottish Government, NHS Scotland, the research sector and industry to enable Scotland to be a long term leader in digitally enabled care

Figure 29. Governance Model for Scottish eHealth



Key principals for a national governance model were established in 2008, and have been refreshed in the two consecutive strategies

As can be seen from the figure, there are a number of key groups overseeing the governance of the eHealth Program in Scotland, namely the:

- The eHealth Strategy and the separate eHealth Finance Strategy are the formal responsibility of **the Head of eHealth Strategy and Policy** within Scottish Government.
- [The eHealth Directorate](#) of the Scottish Government comprises three divisions that are responsible for eHealth Programs: Policy and Strategy, Technical strategy and governance, and Information assurance and governance. The Directorate is guided by the eHealth Strategy and Program Boards which oversee development and coordinated eHealth action.
- **eHealth Strategy Board** - the governance body providing overall strategic guidance and investment approval for the Program.
- **eHealth Program Board** - responsible for the overall management and implementation of the Program.
- **Clinical Change Leadership Group (CCLG)** - established to ensure clinical input into the Program and has a key role in presenting and consulting on the Program with relevant clinical groups.
- **eHealth Leads Group** - provides a link between NHS Boards and the eHealth Program at a management level and is key to the successful implementation of projects at NHS Board level. With budgets held by Boards for nationally used systems, a key delivery mechanism is ensuring this Group continues to act collectively. The CIOs for all 22 health boards meet monthly.
- **Data Sharing Technologies Board** – established to improve the levels of collaboration between care partners and develop a sustainable way forward for data sharing and collaborative working using technology.
- [National Information Systems Group](#) – is the national procurement organization. Responsible for guidance, procurement, development and delivery, testing, and operating eHealth solutions.

In addition to the main strategy document, thematic work plans are developed, such as the Patient Centered eHealth Strategy and Delivery Plan which aims to improve citizens' access to NHS Scotland, and [Information Assurance Strategy](#) giving direction for securing information reliability and governance in the eHealth systems. Individual NHS Scotland organizations have their own local eHealth delivery plans which will reflect national priorities and developments in the context of their own local circumstances.

From 2011-12 a new financing model was introduced in which the majority of eHealth funding will be distributed to Boards rather than allocated on a project by project basis or spent centrally by the Scottish Government. The intention is to increase flexibility and make sure the financing is generated closer to healthcare personnel and patients, which is seen to be important for generating results.

As part, and a result of the choice of the highly collaborative governance model, Scotland has had an explicit focus on competence building on eHealth for the healthcare sector as a whole. This implies both defining what competencies and skills are needed at different levels of the eHealth system. Fr

this, the Academy of Royal Colleges together with NHS Scotland has made a [competency framework for eHealth](#). It also entails drafting strategies for how to recruit and staff up the different bodies accordingly.

## 8.6 Current National Scottish eHealth System

### 8.6.1 Infrastructure

*Scotland's Digital Future: Delivery of Public Service* placed an emphasis on innovation in public service delivery. It promoted a "digital first" approach wherever possible, utilising digital technology to redesign existing services and enable better information access and online transactional services for the public. National approaches and collaboration were proposed across a range of areas including governance structures, ICT procurement, data storage, information assurance and workforce development. Since 2012, developments have taken place from which the eHealth programme will benefit including:

- development of the mygovscot portal infrastructure to simplify and better signpost access to public services information and online transactions;
- the Citizen Account structure and system (myaccount) to enable members of the public to verify their identity and register for online services;
- the cross public sector [Scottish Wide Area Network \(SWAN\)](#) contract for communications infrastructure will support sharing of services and integration within the public sector through providing users with common, shared Virtual Routing and Forwarding technology. As the major partner, NHS Scotland led the procurement;
- the Next Generation broadband programme which will provide both patients and mobile health and social care staff with improved coverage and data speeds to access eHealth systems;
- legislation to enable NHS National Services Scotland to provide technology and procurement services not just to NHS Scotland but across the entire Scottish public sector.

Today electronic messages are exchanged through [SCI Gateway](#), a solution for electronic messaging connecting to the [SCI store](#).<sup>94</sup>

### 8.6.2 Infostructure

In Scotland, [the Information Service Division \(ISD\)](#) of the NHS provides terminology services that deal particularly with ICD-10, OPCS4, READ and SNOMED CT.

ISD gives information on coding and terminology systems, offers training courses, and works closely with the Data Standards Service.

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<sup>94</sup> See more on the [SCI Demonstrations](#) page.

A [data dictionary](#) has been developed and managed by the ISD as a one-stop shop for health and social care data definitions and standards. It includes a generic dictionary, SMR and clinical datasets as well as other standards.

The United Kingdom is a member of IHTSDO (the International Health Terminology Standard Development Organization) and Scotland therefore participates in these activities.

### 8.6.3 Privacy, Information Security, Access Control

Scotland has a dedicated patient ID which is called the [Community Health Index Number](#) (CHI number). The use of the CHI on all clinical communications is mandatory. Current developments involve how to link CHI with personal identifiers in social care, so as to ensure sharing of appropriate information to ensure coherent patient care pathway.

The Scottish Government has been working with NHS Boards to promote safe, effective and appropriate use of information by providing strategic direction through the publication of an Information Assurance Strategy and core guidance including:

- [Records Management: Code of Practice](#)
- [Mobile Data Protection Standard](#)
- [Code of Practice on Protecting Patient Confidentiality](#)
- [Information Governance Educational Competency Framework](#)

### 8.6.4 Shared eHealth Components and Services

[Picture Archiving and Communications System](#) was launched in the NHS in Scotland in 2005, and is now live across the NHS in Scotland, with thousands of images shared each day. It is integrated with the Radiology Information System, which is a national archive of electronic images and radiological reports. The system is managed by National Information Systems Group of National Services Scotland.

[Emergency Care Summary \(ECS\)](#) - is a single, national ICT record system that contains key information from GP records concerning demographic, medication and allergy information. ECS does not create or capture new information about patients. Instead, it copies items of data that already exist in GP practice systems and makes it available to users who need it as 'read only'. It is fully rolled out across the service, and holds information for 5.5 million patients. It enables clinicians and other health professionals in out of hours services, accident and emergency units, NHS 24 and the ambulance service to access important patient information during unscheduled and emergency care situations. In 2010, the electronic palliative care summary (ePCS) was included within the ECS. It holds a range of information on the patient's wishes concerning their care and end of life wishes, including place of care. It aims to reduce the number of end-of-life patients taken to hospital unnecessarily. In 2012 it was agreed that the ECS should be used in scheduled care to support medicines reconciliation.

Also in 2012, the [Key Information System \(KIS\)](#) became an extension of the ECS. This is designed to support patients with long term conditions or who have anticipatory care plans in place. KIS contains information from the GP Practice, including:

- patient demographics
- details of staff involved in the care of the patient
- the patient's current situation, including main diagnosis and current issues

- carer and support details
- information and recommended actions for out of hour's clinicians

A key aspect of KIS is that the clinician is required to work collaboratively with the patient to create the information that is included on the system. This is a change in emphasis from traditional systems where the clinician decides unilaterally what goes on patient record systems.

[National Patient Management System \(PMS\)](#) - provide both in-patient and out-patient efficient patient scheduling and waiting time management, with additional features such as online test ordering/ results reporting and scope for further functional modules such as A&E, theatres, electronic prescribing and maternity. Thus, it is a secondary care system that seeks to share information across the hospital according to the patient trajectory. A consortium of five NHS Boards, supported by the Scottish Government, undertook a joint procurement and selected the TrakCare PMS. The eHealth Strategy 2011-17 states that the benefits of this collaborative approach have been significant: "driving the convergence and standardization of IT systems at substantially lower cost than could be achieved if Boards were working locally and individually, while maintaining the local ownership that is vital to the successful implementation of these complex changes.

[ePharmacy](#) – Central to the configuration of ePharmacy systems is the ePharmacy Message Store (ePMS), which is the gateway and store for encrypted messages sent between GP Practice, community pharmacies and National Services Scotland's (NSS) Practitioner Services Division (PSD). It is adaptable for future developments and has been designed so that the data collected can be accessed through an electronic health record in the future. Other parts of the program include:

- Connecting all community pharmacies to the NHS Net and allowing access to NHS Mail. Every Community Pharmacy is connected to the N3 network and can access all the ePharmacy services.
- Developing a central patient registration system, in order that patients can be registered for the Minor Ailment Service and the Chronic Medication Service. This uses the CHI as the patient identifier.
- Introducing the ETP system between GP Practices, community pharmacies and PSD, which aims to reduce transcribing errors, modernize service delivery and increase the efficiency of the processing of prescriptions.
- Developing the Pharmacy Care Record system, a web-based care planning tool that is aimed at assisting pharmacists in providing pharmaceutical care to patients with long term conditions. It was developed and deployed nationally to support the Chronic Medication Service (CMS).
- Developing more efficient payment processing systems. NSS PSD utilizes the electronic prescription and claim information to deliver significant efficiencies in their payment processing activity.

The eHealth Strategy 2011-17 states that the ePharmacy program is also "exploring the potential benefits from sharing information on what has been dispensed for a patient, alongside what has been prescribed, through the Pharmacy Care Record, held in community pharmacies, to assist in medicines reconciliation". It is believed this will help to ensure the ECS is an accurate record of what medication patients are taking.

[Hospital Electronic Prescribing and Medicines Administration \(HEPMA\)](#) - is another program being implemented to support the eHealth strategic aim in relation to medicines reconciliation. The purpose of HEPMA is to assist in the proper prescribing, ordering, administration, reconciliation and supply of medicines. It also has an important role in ensuring there is a robust audit trail and in standardizing good practice in these areas. The national approach to procuring HEPMA is being delivered through the national Patient Management System contract on an optional basis.

[Clinical Portal](#) - A key feature of the first and second eHealth strategies is to promote actions that will allow clinicians and other health professionals the ability to see a range of clinical information through a single online location. The clinical portal program is aimed at the secondary care sector. An incremental approach is being taken, with the aim of ensuring all NHS Boards reach a minimum baseline, but which is also flexible to allow NHS Boards who are developing systems at a quicker pace to do so. NHS Boards have agreed to use one national integrated platform for pulling together defined information from different clinical systems, though they are free to select the system or “electronic window” that clinicians will use to access the information. Given the incremental nature of the program, NHS Boards are at different stages of implementation.

### 8.6.5 EHR Landscape

Primary Care IT Systems - electronic patient records used in GP Practices. Up to the early to mid-2000s the key system used was the General Practice Administration System for Scotland (GPASS). Following critical reports and a loss in confidence in it by GP Practices, the eHealth Strategy 2008-11 made a commitment to replacing GPASS and provide funding to enable NHS Boards to have direct contractual relationships with their suppliers of GP systems. The Scottish Government commissioned a consortium of Boards to develop a business case and run the procurement process. This led to two other existing systems EMIS and INPS (Vision) being selected to be on the framework contract, with each NHS Board holding mini-competitions to decide which to deploy. Migration to the new systems was completed in 2012.

In the hospital sector, there are a variety of EHR systems installed.

### 8.6.6 Digital Services for Citizens

In Scotland, citizens that are digitally active are seen as central to effective, integrated health and social care. As part of the implementation of the third eHealth strategy, the Scottish government seeks to digitally strengthen the interaction between patients/citizens and the health and social care services, currently taking a multi-track strategic approach in Scotland:

- Aiming to make personalized health information (including a summarized electronic patient record) and baseline services available to each citizen by 2020. In the meantime, [NHS24](#) and [NHS Inform](#) websites will be refreshed to improve the on-line self-care guides and information already provided. This is happening in close cooperation with patient organizations.
- Consolidating and extension of the portfolio of comprehensive patient platforms for chronic conditions such as [PatientView](#) and [MyDiabetesMyWay](#). These provide digital tools for patients with conditions which best lend themselves to effective self-management and co-production with clinicians.
- Promoting the development of [Primary Care Digital Services](#) for patients by investing £6m into a Digital Services Development Fund.

Eventually, the aim is to bring these strands together through a patient portal.

#### 8.6.7 Secondary Use of Data

Part of the third eHealth strategy was an aim to foster innovation through mobilizing academic and industrial environments in the development of eHealth. One important example for such an endeavor is [Scottish Informatics Programme \(SHIP\)](#), a nation-wide research platform for the collation, management, dissemination and analysis of Electronic Patient Records (EPRs).

Within the NHS, [the Information Services Division \(ISD\)](#), Healthcare Improvement Scotland (HIS) and the Scottish Intercollegiate Guidelines Network (SIGN) drive the national quality improvement work. The ISD and HIS in particular have increased their roles in quality improvement in recent years and also work closely together on measurement, data collection, and analysis.

As for data and measurement, information for tracking and improving healthcare quality is collected across the entire Scottish healthcare system and spread out across several actors. Historically, data collection and registry maintenance has been decentralized and driven by hospitals and clinical networks. Since a couple of years back, however, the ISD has taken over responsibility for running most national registries and audits. The national strategy is to try and link existing records together with added finesse, rather than start new registries. A general note is to not confuse national quality measurements and quality registries. Disease-specific quality registries are few in Scotland, while national measurements of quality are made systematically to improve healthcare.

Researchers can access most registries hosted by the ISD and other organizations, but sometimes need permission from different Health Boards and the Privacy Advisory Committee, which can complicate the research process. However, projects are under way to try to facilitate access to both primary and secondary care data for researchers.

There is also a general understanding around the importance of having publically available data. The main data that are regularly published in the media and known to the public are standardized mortality ratios (SMRs) and data on waiting times.

## 9 Spain

### 9.1 Gathering Information on the Spanish eHealth system and Choosing Case Study

In the Spanish case we have chosen to concentrate our study on a regional development project rather than developing a full-fledged analysis of the Spanish national eHealth system. This has to do with the specific political situation in Spain with a high degree of regional autonomy, and a regional approach to the organization of healthcare services. There are large differences among the different Spanish regions with regard to the implementation and use of eHealth solutions. The Southern region of Andalucía is among the most developed. In the following we shall hence shortly describe the national eHealth strategy, before moving into the Andalusian case study.

The empirical material for the chapters on Spanish and Andalusian eHealth development is gathered through:

Desktop research, May-June 2013 and January-March 2015: Official documents and websites of governmental actors and sector organizations were explored to gather background on the Andalusian healthcare system, eHealth strategy, key actors and initiatives.

Study trip: A study trip was organized in January 2014. The event was organized around the following program:

PROGRAM FOR NORWEGIAN STUDY TRIP TO ANDALUCIA WINTER 2014		
<b>Tuesday</b> 21.1.2014	IT Centre of the Andalusian Public Health System	<ul style="list-style-type: none"><li>• Overview of the Andalusian Healthcare System</li><li>• Presentation of the Díraya system</li></ul>
	Hospital Universitario de Virgen Macarena	<ul style="list-style-type: none"><li>• Díraya in Emergency department and Inpatient department</li></ul>
<b>Wednesday</b> 22.1.2014	Primary Healthcare Centre	<ul style="list-style-type: none"><li>• Díraya for GPs</li><li>• ePrescription module</li><li>• Statistical data and reports for managerial and administrative purposes</li></ul>
	Pharmacy	<ul style="list-style-type: none"><li>• Díraya in pharmacy</li></ul>

On the basis of the information gathered throughout the study trip, the report was updated focusing on the Andalusian experience with realizing policies in practice.

### 9.2 Demographic Data and Political Tradition

Population (01.01.14)	46,5
Area (km <sup>2</sup> )	505,990
Political tradition	Unitary parliamentary constitutional monarchy, with decentralized autonomy to 19 autonomous communities
Administrative levels	State, Autonomies, Provinces, Municipalities

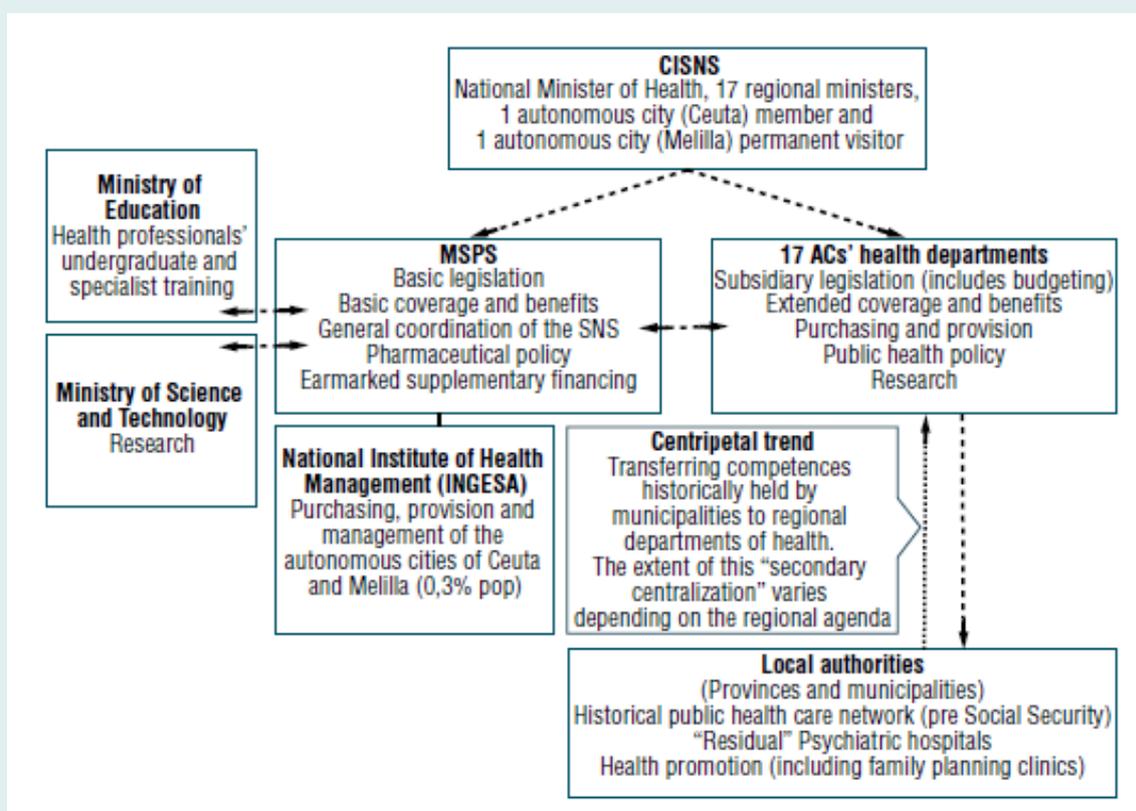
### 9.3 Key Figures for Healthcare System

<b>Health status</b>	
Life expectancy at birth (years)	82.5
<b>Expenditure on health</b>	
In percent of GDP	9.4
Per capita (USD purchasing power parity)	2998
Public financing (% of total expenditure)	73
Private financing (% of total expenditure)	
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	3.8
Practicing nurses (per 1000 population)	5.2
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	
Hospital discharges (per 1000 population)	
Total hospital beds (per 1000 population)	3
Average length of stay, all causes (days)	

Source: OECD 2013

### 9.4 Financing, Organizing and Governing healthcare

Figure 30. The Spanish Healthcare System



Source: WHO, HIT Series

Healthcare in Spain is largely public and largely financed by taxes, which provides nearly universal healthcare, free of charge.

The Spanish healthcare system is organized by national and regional entities. [The Ministry of Health, social services and equality](#) is the key authority responsible for the general coordination of public health and healthcare services and for drafting basic health legislation and policy, international agreements concerning healthcare and the regulation of pharmaceutical products.

Healthcare planning, health attendance, and public healthcare are managed by the 17 regional ministries or departments of health managed by the country's 17 autonomous regional governments with primary jurisdiction over the organization and delivery of health services within their territory. This also means that health expenditure is mainly determined by regionally. In essence, the national Ministry of Health and Social Policy has the challenging mandate of playing the core role in the coordination of the national healthcare system spread through 17 regional health systems, which are accountable only to the regional parliaments and thus not hierarchically linked to the national level. Most of the dialogue takes place within the Inter-territorial Council of the national health system comprising the 17 regional ministers of health chaired by the national minister.

Regional health departments fund primary healthcare and hospitals, including their IT services, through a budget that accounts for 30 % to 40 % of the regional governments' total annual budgets. Private companies manage some of the public hospitals in some of the regions and may be paid on a per capita basis. All GPs' offices and primary healthcare centers, outpatient specialized clinics and physicians' offices, as well as 80 % of hospital care, are publicly owned and managed.

During the 1980s and 1990s, Spain's health system underwent major change, achieving a significant extension of coverage, developing a new reformed primary healthcare network and rationalizing both financing and management structures. The first contact point of the population with the health system is the GP, who acts as a gatekeeper. Prior to the reform, the traditional system of primary healthcare delivery consisted of a solo practitioner working part time; the reformed model is based on a primary healthcare team working full time on a salaried basis.

### ***9.5 Spanish eHealth: Past, Present and Future***

It is described as challenging to realize centralization projects in Spain due to high degree of regional political autonomy and regional variation in economic situation, IT maturity, culture and organization of healthcare. The regions have, thus, wanted to maintain an independent responsibility for healthcare innovation.<sup>95</sup> The result is regional eHealth implementations that are not interoperable and minimal data-reporting from regional to national level. The global lack of data creates challenges for inter-regional mobility and collaboration between neighboring regions in the healthcare system.

The Spanish healthcare system (NHS) struggles to balance between making the regions responsible for healthcare services and maintain central governance. ICT plays a key role in this balancing act.

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<sup>95</sup> <http://www.euro.who.int/en/about-us/partners/observatory/health-systems-in-transition-hit-series/countries-and-subregions/spain-hit-2010>

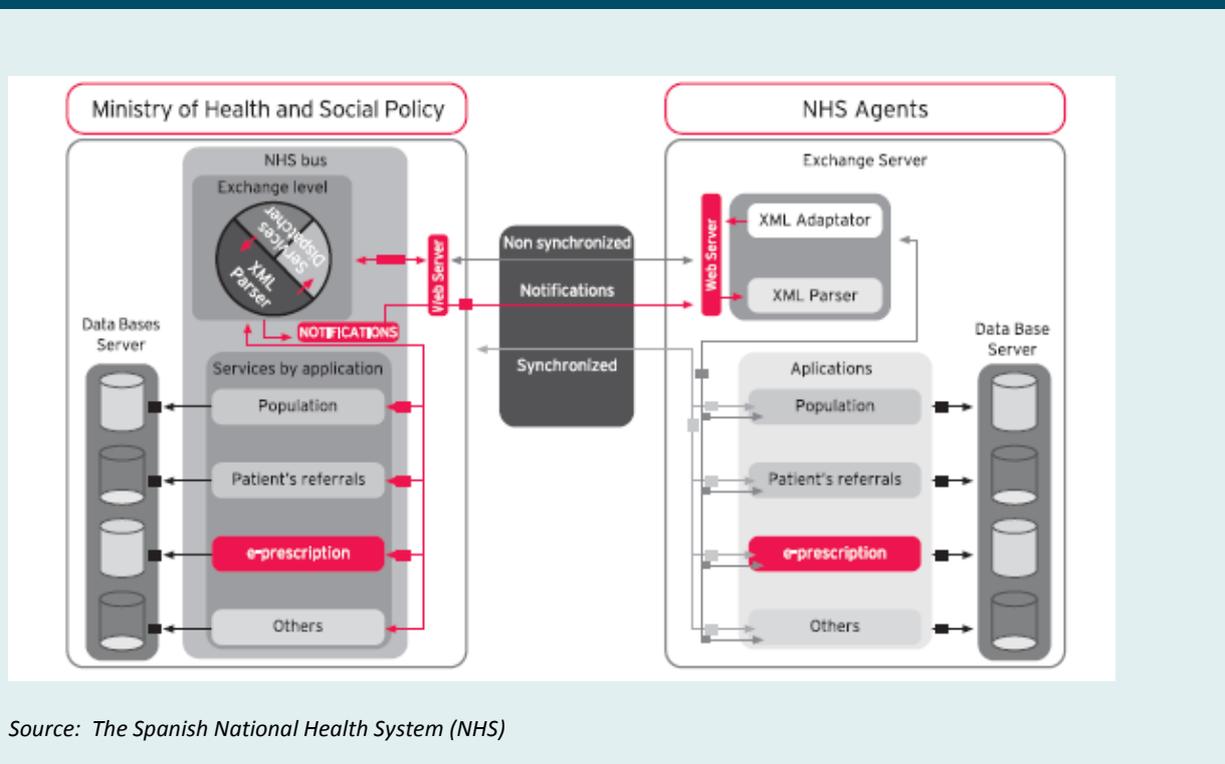
### Timeline

**2005:** The Spanish government launches «[Plan Avanza](#)». The aim is to improve the economic productivity by developing the knowledge- and information society. Health is part of the Plan Avanza, and the government aims to exploit the potential of ICT in pursuit of patient interest.

**2006:** [Healthcare Online Program](#) is launched, a collaboration between national health authorities, autonomous regional authorities, and the ministry of industry, tourism and commerce. The program is developed in response to the Plan Avanza, as well as the Ministry of Health's Quality plan which positions the ICT effort within healthcare in relation to the overarching health political objective for improved quality and patient safety. Key for the ongoing work is the agreement that:

- Prioritized key projects for the program: eID; EHR; and ePrescription
- Harmonizing of national and regional health agendas
- Specification of financing model
- Project management and administration is delegated to the specific agency Red.es
- Consensus regarding general objectives, as identified in the different regional eHealth strategies
- Close collaboration with IT health industry in order to share knowledge in strategic areas to secure development and implementation projects succeed
- Commitment and accountability for all stakeholder – nationally and regionally – in order to secure benefit realization

Figure 31. The National Node for Exchanging Information



The overall objective for Healthcare Online Plan is to ensure access to certain information types in the EHR, regardless of location in NHS by using an interoperable identity card that identifies patient, and information stored about this. The work is divided into two phases:

### **2006 – 2009: Development of infrastructure and IT services**

- Legal framework for collaboration between regional and national authorities
- Governance model
- Project management and framework for follow up and evaluation
- Synchronization of regional health cards with the central citizen register
- Consolidation of a secure and accessible central node

The national system based on a central node (See figure 30) enables information exchange for instance between the following databases: Citizen registry, health personnel register, cohesion fund, prior instructions, ePrescription and EHR. NHS IT services are based on a framework for interoperability that enables integration with regional health information systems. Exchange of messages is based upon XML-standards and platforms and applications remain independent. In other words, NHS builds on a service-oriented architecture (SOA) that supports decentralized information and service exchange. Through the «health net», the XML-switch point is the central node that links all different agents (regions, central authorities, etc.) that need to exchange information with the NHS and vice-versa.

### **2009 – 2012: Focused development of ICT projects**

- Develop NHS EHR to enable information sharing (clinical and ePrescription) between regional health services and NHS central node
- Stimulate regional development and implementation of EHR and ePrescription

The successful implementation of the central node model is preconditioned by the regions following the defined standards in order to make information available centrally. This is only partly realized today, since many regions, in particular the most progressive within eHealth, have chosen to develop their own innovation projects.

On this backdrop, rather than pursuing the study of the Spanish, national architecture, we will go in-depth on one, regional case study. In the following we shall take a closer look at the development of a shared, regional eHealth system in Andalucía.

## 10 Andalucía

In this chapter on Andalusian eHealth we will use the empirical material gathered through desktops research and the study trip to Seville to describe the past, present and future of the Andalusian eHealth system. Obviously, the description is not exhaustive. The content of this report reflects the knowledge needs of the Norwegian *One patient – One record* program. When situated perspectives and viewpoints are expressed, we highlight this by referring to the source. To validate the findings, the Andalusian host institutions will be invited to add their comments and corrections to the report.

### 10.1 Financing, Governing and Organizing Healthcare

Throughout the 1980s, Spain separated healthcare from the social security system and established a NHS model for healthcare, including full responsibility for public health, public network of hospitals, ambulatory clinics and rural offices. Healthcare became a basic right for the entire population.

The Andalusian healthcare system is mainly public and financed by taxation. Citizens are entitled to universal access to services. Only 2 % have a private insurance and about 7 % a combination of private and public health insurance. Andalucía is categorized as a region under development within the EU system, with socioeconomic challenges being enhanced by the financial crisis which has led to high unemployment rates and increased the burden on public system. The financial crisis is affecting the salaries and limits the room for hiring new staff. The main principles regarding the public healthcare system and universal access to healthcare are, however, not affected.

The governing of the Andalusian healthcare system is centralized at a regional level. [Servicio Andaluz de Salud](#) (SAS) (In Spanish) is responsible for healthcare services in the region, under the supervision of the Ministry of health in Andalucía and the regional authorities, Junta de Andalucía. SAS administrates the whole public primary healthcare service and specialist healthcare service.

There are 770 municipalities within the region of Andalucía. The municipalities have no decision-making power, nor do they provide healthcare services. They do, however, represent their citizens' interests on healthcare by negotiating with the regional authorities on the governing and content of healthcare services.

Primary healthcare services employ 20,810 people and are characterized by the availability of integrated health services including preventive, curative and rehabilitative care. It is also responsible for the promotion of health, for health-related education, and for monitoring the environment with respect to health. In 2007 there were 1,146 primary care centers in Andalusia.

Specialist care employs 62,322 persons and provides the technical and human capabilities appropriate to diagnosis, treatment and rehabilitation for conditions that cannot be handled at the primary level. SAS manages and operates 29 hospitals throughout Andalusia. In addition they manage and operate numerous more specialized facilities such as ER, Mental healthcare program, and transplant center.

Long term care, as offered in home care, nursing homes and day care centers, is the responsibility of the social welfare authorities and, thus, falls outside the area of responsibility of the healthcare system. Most nursery homes are privately owned – paid by regional authorities through social welfare department. At hospitals there are house doctors who visit a patient at home in the beginning of a chronic care trajectory. Later on, the social services take on the responsibility for these

patients groups. That said, integration of healthcare and social services under the label “active aging” is an area under development in Andalucía.

The Andalusian government has introduced the legal right to a guaranteed maximum waiting period for surgery (120 days), diagnostic tests (30 days), and specialized consultations (60 days). The waiting time guarantee has been an important political driver for the development of eHealth in Andalucía. If public healthcare organizations do not deliver within the guaranteed time, patients are entitled to have expense for treatment at a private sector provider reimbursed. Given the political emphasis on maintaining a universal, public healthcare system, hospitals mobilize great efforts to avoid this from occurring.

The 4<sup>th</sup> Andalusian health policy plan from 2013<sup>96</sup> gives political direction for the further development of Andalusian eHealth. The focus of the plan is on quality of care, process re-engineering (clinical guidelines) and competence based management. eHealth solutions play a key role in all these areas. In the following we shall take a closer look at the development of an Andalusian eHealth system, before going into the description of its components and services.

### ***10.2 eHealth in Andalusia: Past, Present and Future***

*Díraya – Arabic: Knowledge* – is the eHealth system developed by and for the public healthcare system in Andalucía which covers total the population in Andalucía.

The starting point for the Díraya project was the problem associated with integration of a large quantity of small, specialized systems. The objectives were:

- 1) One citizen - One record: Integration of all patient information – independent of service areas or individual professional documenting the information – in one, unique EHR system, accessible regardless of time and place.
- 2) Support collaboration by monitoring patient flows to ensure efficient coordination of all treatment where multiple actors are involved in diagnosis and treatment.
- 3) Structure all relevant information – applications follows the same design principles; same tables, codes and catalogues.

The Andalusian governance model for eHealth is described as the most centralized in Spain. SAS finances and decides on IT systems. The strategy is to regionalize everything. It demands strict governance and coherent organization throughout the sector. Healthcare organizations do not have an IT budget or an IT department. Hospitals no longer draft IT strategies or hospital strategies. The trend is that the largest hospital chooses a solution, and the rest has to follow. The purchasing for hospitals and primary care centers are managed by provincial units, in accordance with centralized (regional) contracts. Demands for health IT systems are managed through a central committee with participants from local enterprises. The development is going towards increased centralized decision-

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<sup>96</sup> Only available in Spanish, [here](#)

making structure and consequently system solutions. In practice, the Andalusian healthcare system is governed as *one* enterprise.

### **Timeline**

**1990-1995:** to understand the development of *Díraya*, we must first consider the work with the local information system *la Tarjeta de Afiliado a la Seguridad Social* (TASS). TASS was developed in relation to a reform of sick leave reimbursement. Based on authorization from a family doctor, sick leave money was paid out from the national Ministry of labor and welfare (MoL). Increasing expenses due to increasing sick leave, led to a desire for stronger control over the authorization process by MoL. In order to establish tighter couplings between sick leave reports and reimbursement of sick leave money, MoL saw the need for an information system that could give a coherent and up to date quality checked information from the family doctors. MoL thus financed the development of TASS in order to get access to sick leave applications fast; electronically and in real time. In the process, SAS convinced MoL to include EMR functionality in the system.

**1997:** The system is linked to an eID card and implemented. In the course of a few years, 1,000 databases are established.

**1998:** SAS decides to integrate the primary care databases, and the planning of *Díraya* begins. The aim is for healthcare personnel to share information in order to increase the quality and continuity of healthcare services, and to improve public health work in general. Several factors were decisive:

- TASS was limited to external communication of sick leave forms. With MoL as the owner of TASS, SAS did not have any real influence over the decisions that were taken regarding system functionality and interoperability.
- As part of an overall strategy to increase efficiency and quality of healthcare in the region, SAS wanted to develop a system for sharing of clinical and administrative patient information.
- The distributed TASS database did not support the strategic goal of SAS, in particular not when it came to information sharing as support for public health work, clinical standards and coordination of care.
- Too many patient records existed in the primary healthcare sector. Totally around 10.5 million records, for a population consisting of ca. 7 million people, a redundancy rate at ca. 30 %.
- The information stored in TASS was not consistent and hindered the development of ePrescription, and use of data for public health work.

**2001:** Work on a citizen register starts.

**2003:** Primary care sector and pharmacies start using *Díraya*. Every primary healthcare center has its own database that operates on a local server. The system is used to administrate bookings, enterprise administration, and EMRs. Family doctors, pediatrics, nurses and administrators are the primary users. The system is well received and soon demands for increased functionality surface, functionality that can support quality improvements across enterprises.

**2004:** Official roll out of ePrescription initiated. Implementation of the complete centralized version of *Díraya* is launched.

**2005:** Electronic booking is introduced for primary care and specialist care services. The introduction of the waiting time guarantee is a main driver for the accelerated development and implementation of Díraya, including the electronic booking system.

**2006:** The first EHR is used in ER and outpatient clinic. [InterS@S](#) (webportal) is accessible for patients that want to book an appointment with primary care service.

**2007:** SMS booking system for primary care service is launched.

**2013:** Shared EHR system is implemented in 735 primary healthcare centers and 27 hospitals and covers 7, 7 million citizens (95 % of population). More than 200,000 acute cases, 8 million ePrescriptions, 7 million bookings are handled every month.

**2014:** Work ongoing to launch new version of Díraya:

Functionality	Software development	Systems and infrastructure
<ul style="list-style-type: none"> <li>▪ Unification of interfaces and visuals styles</li> <li>▪ Support for health process management with health IT systems</li> <li>▪ Integration with national node</li> </ul>	<ul style="list-style-type: none"> <li>▪ Complete the process of modularization of applications</li> <li>▪ Finish the technological evolution of environments</li> <li>▪ Increase the control of developments (from the code repository to the total control)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Migration to a centralized environment to all the infrastructures that provides corporative solutions</li> <li>▪ Virtualization</li> <li>▪ Full replication between nodes (Seville and Malaga)</li> </ul>

#### About the development and implementation of Díraya

Under the coordination of SAS, theme specific expert groups consisting of 500 healthcare personnel were established in order to reach consensus regarding structural demands, specifications, and definitions. The process of user involvement was experienced as demanding, but is considered the key success criteria for the development and implementation of Díraya. Rather than slowing down or hindering the realization of a large and complex system, the result was:

- 1) Early identification and handling of the majority of the challenges in the development phase led to fewer and less cost demanding errors and modifications during the implementation phase.
- 2) Active listening and constructive use of ideas, knowledge and experience from end users contributed to identify and meet needs, which led to acceptance of the project and resulting solution.

Díraya was designed for gradual implementation, both in terms of geography and functionality, starting with primary care service (90 % coverage in 2007) and later acute care and outpatient clinics. The transition from a local to a central information system was demanding for several reasons.

**In primary healthcare**, the technical introduction of Díraya went by rather uncomplicated. In 70 % of the cases it was possible to migrate the EHRs automatically. In the 30 % where this was not possible, manual transfer was needed, first having to map information to actual patients. Criticism raised as the procedure gave the impression that data was lost. The manual transfer of data demanded a support team of 100-150 persons the first three weeks. In addition to the technical support team that was present at the primary healthcare centers in three weeks during the introduction of the system.

**In specialist healthcare**, implementation was more technically challenging. While most hospitals had PAS, they were not accustomed to clinical IT systems. In addition, every hospital had its own vendor. Some hospitals were in the midst of implementing a new EHR system.

Up until 2010 70 million euro was invested in Díraya, including funding from the European regional development fund (ERDF).<sup>97</sup> By allocating the financing of healthcare services delivered in Andalucía to SAS, the regional Ministry of Health takes the role as a third-party financier. The IT vendor [INDRA](#) was the development partner for SAS and other vendors contributed to several different tools integrated in Díraya. SAS owns all rights to the programs and also have full control over development process. That means that if one vendor drops out of the project, they still have control of the information and can continue the development with new vendors. CEGES – the system and technology management center for the Andalusian healthcare system is outsourced and operated by Accenture.<sup>98</sup> Today the primary care centers are paper-free environment. Hospitals however, still have a way to go. Even though there is a system in place they still need to complete roadmap to fully exploit the system. Following ten years of development and implementation, results are now starting to surface. Commissioned by the European Commission, [Empirica](#) conducted a cost-benefit analysis of Díraya in 2009. The conclusion shows positive effects related to quality and efficiency both for patients, healthcare personnel and authorities. In particular, the report points to reduced waiting time/response time. The study expected that the cost/benefit ratio in 2010 would reach +1.77, which means that every € 100 of the investments produces € 277 in socioeconomic benefit. The regional authorities points to good results from standardizing laboratory system making it possible to ID every sample, trace lost samples and enhancing interpretation possibilities. In addition, ePrescription is also considered a success factor, helping save 7.500.000 euro annually.

The ICT budget for the Andalusian health authorities in 2014 is 52 million euros. They do not consider it an option to buy Díraya in the EHR market. Nothing exists that would meet their requirements because the solution that has been developed is too tightly integrated with the specifics of the Andalusian healthcare organizations.

The user satisfaction for the Andalusian healthcare services is among the highest in the country. The regional health authorities explain that, apart from a small dip during the implementation phase, the level of user satisfaction has remained the same throughout the Díraya project. This is considered a strong point, as expectations have increased considerably throughout the project, and it has been demanding to develop a system that patients would also validate as successful.

As already mentioned, the strategy of the Andalusian healthcare system is to centralize decision making and control. To enhance control over the organization, the recruitment of staff is centralized. The Díraya project employs about 30 people in the central team inside the IT department, and 350 all

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<sup>97</sup> SAS developed Díraya by building on their knowledge and experience with the development of TASS, these prior initiatives are therefore included in the total investment for Díraya.

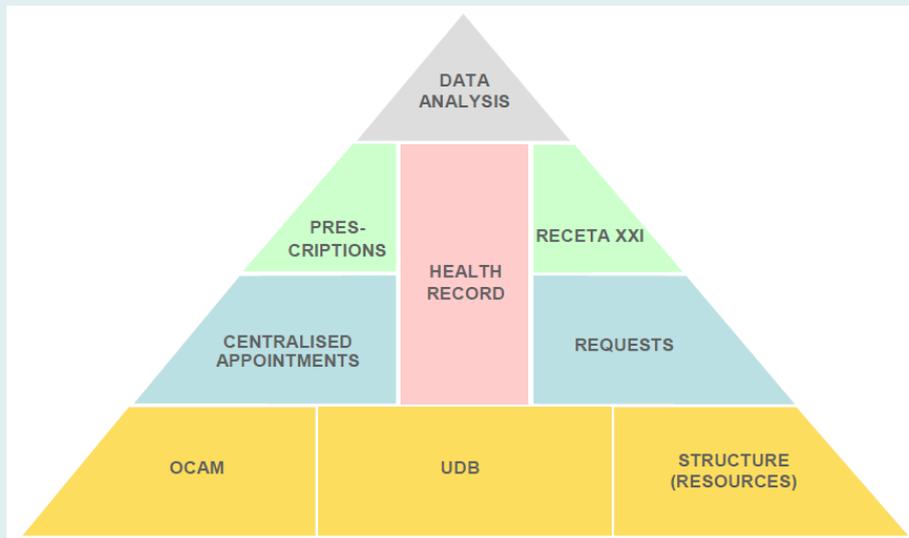
<sup>98</sup> For more information about the role of Accenture in the Díraya project see:

<http://www.accenture.com/SiteCollectionDocuments/PDF/Accenture-Service-Oriented-Architecture-Transforms-Healthcare-IT-Andalucia.pdf>

together in Andalucía. In addition the vendors and companies offering support services make up around 350 persons. According to the authorities this offers some major advantages. With *one* healthcare system, in which costs and benefits are shared, there is a collective incentive to operate efficiently and improve quality in all parts of the healthcare organization.

### 10.3 Díraya

Figure 32. Architecture – Modules that Comprise Díraya



Source: Junta de Andalucía

Díraya builds on a centralized architecture for primary care services and a dualistic architecture for the specialist care services. Work is now ongoing to centralize all primary care data, which is today being duplicated in Malaga.

Key criteria for the conceptual choice:

- Facilitate maintenance and administration
- Strengthen system security
- Simplify updates of tables and versions
- Cost efficiency

Díraya consist primarily of semi-structured data and different related modules that shares data. The architecture is built on three cornerstones (see figure 31):

- **User Database (UDB)** gives every citizen a unique identification number that is linked to all patient information.
- **Centralized Operator Access Module (OCAM)** is the portal to Díraya for healthcare personnel. The module identifies the person with an access code and offers access to the modules for which she/he is an authorized user. Single sign-on system for all modules.
- **Structure module** consists of departments and functional units, as well as physical locations in primary and specialist healthcare service. Gives the user an overview of available resources; beds, boxes, clinics, etc.

The EHR system is “the heart” of Díraya. The concept is a HIE solution. The strategy is not to have *one* EHR system, but a set of EHR modules, integrated through HL7, enabling healthcare personnel to handle clinical information differently, from any location in the network. Functional map including administrative systems and mailbox for clinicians is all included in the same system.

Data for central storage is gathered through the following modules

- OCAM, health personnel register
- UDB, citizen register and personal information
- STRUCTURE, resource register
- Centralized booking
- REQUEST AGENTS: administrates requests for, and answers to diagnostic tests
- RECETA XXI, ePrescription
- MTI, information handling module
- EHR

### 10.3.1 Infrastructure

IT developments in the Andalusian healthcare system require a public procurement/tender process, and can involve several vendors. The component development, system development, and system integration for Díraya has been done by a national vendor, [Indra](#).

Hosting and technical operation and maintenance at a central level is mainly run by SAS. Local operation and maintenance of niche systems is operated by vendors contracted by SAS. Despite a large number of contracts, SAS has secured ownership and are in charge of the system portfolio.

### 10.3.2 Infostructure

Information is organized according to a hierarchy with different configurations adapted to the type of healthcare personnel using the system. There are three information blocks:

- 1) **Basic health information (centralized data):** socioeconomic relations, civilian status, medical history, allergies.
- 2) **Diagnostic and therapeutic information (distributed data):** inter-consultations, analyses, diagnostic tests, medication, examination forms.

Information block 1 and 2 is divided and build on information from the modules used in the different service areas (primary care, outpatient clinic, ER, etc. The difference between them is that the consultation forms makes up a third information block.

- 3) **Medical records (distributed data):** The forms contain documentation from consultations, information that is being fed into the two other blocks. Even if they have shared components, the forms are tailored made for GPs, nurses, care workers, etc.

Key to Díraya is to have strict rules defined to ensure that integration is possible. No one is included in the system if they do not adhere to integration standards. Integration between the different modules in Díraya is done by HL7 v2, 5. CITAWEB is a public agency dedicated to work on integration and certification. Their role is to work with the healthcare enterprises to develop specifications for developments. They then take an intermediating role in the development of HIE contracts with the approximately 100 vendors active in Andalucía. The 36 vendors offering fully integrated systems, have their systems integrated through an integration platform. Very small systems, such as

spirometers, are not possible to integrate and tweaking is needed in order to ensure operation with other systems.

The system based on integrations offers challenges with regard to updating and improving installed solutions, and developing and installing new ones. SAS explains that they have more than 20.000 prescriptions every ten minutes, thus, there are large risks involved with updating and renewing system. Several months of testing, system validation, and functional testing is needed even before introducing a pilot.

The EHR system is largely based on free text. Some codes are developed for standardized patient trajectories/best practice, however this is still an area under development.

Documentation in primary care is based on ICD-10. Most records, especially in primary care, are semi-structured, and hospital records are now been structured tighter. The current structure is developed by SAS, and as the paper record was already structured in narrative blocks and with some codes implemented, the migration to a structured EHR was not experienced as complicated. While there have been talks of using SNOMed CT, SAS reports that it is not yet on the roadmap as it is considered too complex, regardless of its potential for business intelligence solutions.

Currently, there is no shared information model in the Díraya system. There are different models for primary care sector, hospital sector and emergency services. The service areas are connected through integration. The aim is, however, to move towards a common information model. The system implements service buses, one shared across the region, and one at a local level.

Díraya makes it possible to relate consultation forms, the diagnostic and therapeutic elements in episodes and processes in order to develop decision support. Such functionality is, however, in an early phase of development.

### **10.3.3 Privacy, Information Security, Access Control**

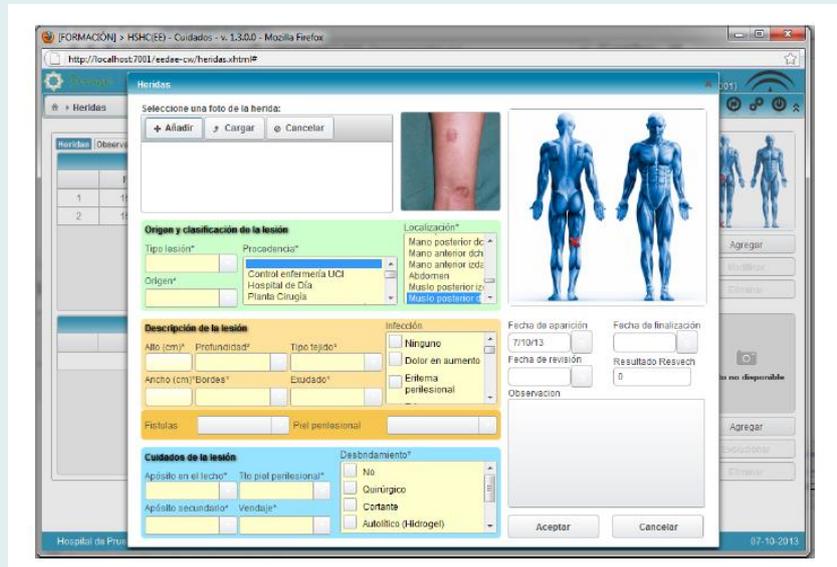
Díraya uses a role based access control system. The health personnel register (MACO) module gives the user access to map of applications in any organization. Each organization has a data responsible that authorizes rights at the local level. The functionality of each role is decided centrally – a neurological doctor in Seville has the same profile as a neurological doctor in Granada. The resource register (STRUCTURE) shows the locations and services available that the roles belong to, and can be active within.

The Díraya system gives the professional access to profile and agenda of colleagues, as well as to the general database. Healthcare personnel can access any patients without an individual agreement of consent. All doctors can consult with a patient and document in the EHR, however, only the family doctor can accept a diagnosis – highlight it or archive it. Since health information is considered the property of the patient, the information follows the patient when moving or changing GP. The responsibility to approve information is then transferred to the new GP. However, the system will still indicate that the patient used to have another responsible GP in order to be able to trace the medical history. When healthcare personnel at a hospital need patient information from Díraya, a contract has to be written between the enterprise and the patient. Only the GP has direct access to the patient's record.

There is an audit log in the system. Patients can request the log. Misuse would lead to prosecution. In general, security breaches are said to be rare.

### 10.3.4 Shared eHealth Components and Services

Figure 33. Screen Dump from the EHR System for Primary Care in Díraya



Source: SAS

Primary care operates one, shared EHR system for the primary care sector and another for the hospital sector. In addition, a shared regional PACS system is implemented.

The Díraya system is based on Windows 2008. With a Citrix solution, all authorized users can access the system through any machine in the healthcare service. There are different modules available on the desktop. Through a scroll down menu it is possible to assemble functional modules according to the specific professional role(s) of the user. For a GP there is for instance an ER module for log on after 20:00, one module for regular consultations and so on.

Through the EHR system, users can access a window which displays the information considered most crucial for sharing; “the magic window” (La Ventana Magica). The window gives a quick glance to the patient’s diagnosis, treatment plan, and critical information about allergies and contraindications. This functionality is highly appreciated among the clinical staff, as an effective overview of the patients contact points throughout the healthcare system. However, because the Díraya system contains large amounts of shared information, a problem is the lack of a robust search functionality allowing the users to find information behind the “Magic window”.

It is the GP, in collaboration with the patient, which makes decision with regard to information sharing. Together patient and GP decide what should be written in the EHR system, how to present the information, and, thus, what should be made available for other actors. This is seen as a mean to distribute responsibility locally and is also intended to create flexibility with regard to different needs with regard to information sharing.

In the presentations from the Andalusian team, the hospital doctors emphasized the value of having access to the GP record. Given that the primary care center is more familiar with patients, their records are also a source for longitude and contextual information which support specialist assessment.

In order to provide their patients with better treatment following a hospital discharge, the GPs want online access the hospitals knowledge base, consisting for example of support tools and protocols, specialist assessment, and reports from occurrences at hospital. This is seen as key to build and share competence between the levels of the healthcare system, thus, integrating processes at hospital and primary care centers stronger.

Pharmacists/pharmacies are important for quality control in the Andalusian healthcare system. Private pharmacies use the Díraya system and its ePrescription module. When citizens visit the pharmacy, they slide their health card and the pharmacy can access all the patient information. At the same time, the system starts harvesting information about what is being dispensed. The health card only holds personal information, there is no medical information stored on the card. The view of the patient's medication list includes decision support tool with warnings for certain drugs such as antibiotics, high-price, high-risks, etc. For patients who use more than 10 drugs there is controller function at a regional level, performed by a pharmacist in collaboration with regional authorities/medical responsible for centers. Prescription handbooks are integrated in the EHR system.

Hospitals have their separate laboratory systems. There is barcode tracking system for laboratory tests and a request system that is integrated with all local laboratory systems. However, attempts are made to reduce the number of lab systems to four through public tender. The doctor must confirm in the patient's record that the test result has been reviewed. Healthcare personnel have access to list of all tests that have been performed. It is also possible to view pictures both at GP office and hospital. Digital access to test results, allows for better preparation of consultations.

In Andalucía there are about 80 defined, standardized healthcare processes (for instance on autism, COPD and diabetes) developed by each areas clinical frontier, which is meant to secure acceptance in the broader healthcare community. The procedures are supported by decision and process support tools that give warnings if standard pathway is not followed up. However, this is still in an early phase of development. Mainly, current installations are developed for primary care services.

#### **10.3.5 Digital Services for Citizens**

According to national law, health information is the property of the citizen. Through the web based portal ClickSalud citizens can access health information and services such as their EHR, list of active medication, critical information about allergies, implants etc, hospital discharge notes, access to laboratory and radiology tests. ClicSalud also offers an online booking system and gives access to healthcare related mobile applications.

To use the portal and belonging services you need a digital certificate. Since you must be 18 years old in order to sign the certificate, you must also be 18 years old to use the system.

In addition to this online service, a call center is established The "Salud Responde" provides patients with medical counselling, follow up fragile patients, and follow up after discharge.

Through the EU funded project [PALANTE](#), telecare solutions have become an integrated element of ClickSalud. A hospital-at-home solution offers digital follow up as patients are released from hospital and going home.

The Andalusian strategy has been to ensure public ownership and control over the portal. SAS considers it too difficult to open the portal for private companies or user organizations because that would involve agreeing on and maintaining a large set of contracts for each application as the hospitals have different contractual conditions.

#### 10.3.6 Secondary Use of Data

Díraya consists of a data-warehouse and online analytical processing (OLAP) technologies which make it possible to make reports, stratify groups, and more. The quality of coding is considered high, which relies on a process of continuous training and data quality control. Most of the reporting is done on a district level, not at the central regional level. All professionals have access to the data that is being reported and listed according to the different modules in the Díraya system (ePrescription, Professionals, Material resources, etc). The data and the possibility to make reports is used both for clinical and administrative purposes.

For clinical purposes, the data in the central repository is used to generate reports on patients, diagnosis and pathways. Based on a set of patient trajectory programs for chronic diseases such as COPD and coronary disease, the information stored in Díraya is correlated to identify high-risk patients and intervene rapidly with check-ups and care interventions. The system also allows you to monitor specific patient trajectories. Starting by identifying a list of patients with a specific diagnosis and then link the information to documentation of interventions makes it possible to monitor the effects of a certain medical program.

On the administrative side, KPIs are developed by regional policy maker and published on the website of the health authorities. Focus areas are outpatient data, waiting time, and clinical data. Constructing different forms of comparative view, it is possible to generate reports on the performance of individual clinicians as well as enterprises and the region as a whole. The reports generated from the data in the EHR system is an indicator on the ability of organizations and professionals to meet certain defined objectives/standards, and therefore linked to the system of financing. 20 % of the organization's income is based on reaching the defined policy objectives, of which 60 % are distributed to the organization and 40 % to individual professionals.

Regional KPIs are also shared with national authorities and published at the website of the Ministry of Health. The national government monitors certain healthcare activities, such as the prescription of medication (expensive, high-risk, overuse, etc.). Data from the ePrescription module is being "read" and measured against policy objectives that are negotiated every year. Data is also used to negotiate with pharmaceutical industry. The data are also the basis for compliance control on individual professionals and healthcare enterprises.

The publishing of KPIs on the website of the regional health authorities is meant to target citizens as well as healthcare professionals and administrators, intended to stimulate an active choice of healthcare provider. However, this has not yet had any impact on patient mobility. It appears that patients prefer to use the healthcare services that are close to home rather than select according to quality measures.

More advanced forms of data-mining is being discussed, especially in the area of public health, but is thus far considered an immature area. There have been attempts of data-mining on the central repository, however, that caused the system to collapse, so work is now done on copies of EHRs.

# 11 United States of America

## 11.1 Demographic Data and Political Tradition

Population (2013)	316 128 839
Area (km <sup>2</sup> )	9 857 306
Political tradition	Federal presidential constitutional republic
Administrative levels	Federal union, state

## 11.2 Key Figures for Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	78.6
<b>Expenditure on health</b>	
In percent of GDP	17.7
Per capita (USD purchasing power parity)	8 508
Public financing (% of total expenditure)	48.8
Private financing (% of total expenditure)	51.2
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	2.5
Practicing nurses (per 1000 population)	11.1
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	4.1 (2009)
Hospital discharges (per 1000 population)	125
Total hospital beds (per 1000 population)	3.05 (2010)
Average length of stay, all causes (days)	6.1
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	31.8
Out-of-pocket medical spending (% of household consumption)	2.9

Source: OECD 2013

## 11.3 Gathering Information on the US eHealth system and Choosing case studies

The empirical material for this chapter is gathered through Desktop research, May-June 2013 and January-March, 2015. Official documents and websites of governmental actors and sector organizations were explored to gather background on the US healthcare system, eHealth strategy, key actors and initiatives. Obviously, the description is not exhaustive. The content of this report reflects the knowledge needs of the Norwegian *One patient – One record* program.

Healthcare in the US is mainly provided by autonomous individual providers, some organized in collaborative networks others are large healthcare insurance organizations. In line with the US political tradition, state intervention is kept to a minimum. Nonetheless, in the last decade national authorities have strengthened efforts to push for digitization of the healthcare sector and secure interoperability across the different healthcare providers. In order to reflect the specifics of the US healthcare system, we have chosen to divide the description of US eHealth in three chapters. We begin by introducing the US healthcare system and the ongoing work with establishing a national IT architecture. In the next two chapters, we will go more in-depth the deployment of health IT by

investigating how two healthcare organizations – Kaiser Permanente and Veteran Affairs Administration – use IT in their respective organizations.

#### ***11.4 Financing, Governing and Organizing Healthcare***

The US healthcare system is described simultaneously as one of the best and one of the poorest in the world. On the one hand, those individuals with private healthcare insurance can benefit from the latest within medical technology, state of the art facilities and top rank in production of scientific papers, also within health information management.<sup>99</sup> On the other hand, while USA spends more on healthcare than any other country in the world (above \$ 2.7 trillion) still large segments of the population is uninsured, quality of care is considered, and the country suffers from large administrative waste.

Government, insurers, and public and private regulators each play an important role in the US healthcare system. Government actors include those at the federal, state and local level. Both the federal and state governments have executive, legislative and judicial branches. However, comprehensive, coordinated, decision-making and system-level planning by the public sector is not widespread in the US, in line with the country's liberal political tradition.

Public and private payers purchase healthcare services for providers subject to regulations imposed by federal, state, and local governments as well as by private regulatory organizations. About half of each healthcare dollar was paid for by the government – a somewhat surprising figure, given the common belief that the system is largely a private one. Market share in health insurance is dominated by larger firms that generally market nationally. The top five firms control 50 % of the market.<sup>100</sup> Overall, the healthcare market is described as highly concentrated, as a result of mergers and acquisitions.

Under the executive branch of the federal government, [the Department of Health and Human Services \(HHS\)](#) plans the largest administrative role in the US healthcare system. HHS includes agencies such as the Center for Medicare and Medicaid that administer the public programs, as well as [the Office of the National Coordination for Health Information Technology \(ONC\)](#).

**Medicare** is a federal program, government financed through income taxes, that covers individuals aged 65 and over, as well as some disabled individuals. Services covered are hospitals, physicians, prescription drug benefit. There are many gaps in the Medicare coverage, including nursing facilities and hearing or vision care. Because of this the vast majority of enrollees obtain supplemental insurance. Overall, seniors pay about 22 % of their income for healthcare costs despite Medicare coverage.

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[http://www.scimagojr.com/countryrank.php?area=3600&category=3605&region=all&year=all&order=it&min=0&min\\_type=it](http://www.scimagojr.com/countryrank.php?area=3600&category=3605&region=all&year=all&order=it&min=0&min_type=it)

<sup>100</sup> United Health Group, Wellpoint, Aetna, Healthcare Services Corporation, and CIGNA.

**Medicaid** is a program designed for the low income and disabled. By federal law, states must cover very poor pregnant women, children, elderly, disabled and parents. Childless adults are not covered, and a large proportion of the low income group still earns too much to qualify for Medicaid. The states are responsible for administering the Medicaid program, which is funded jointly by the states and the federal (57 %) government by taxes. Medicaid offers a fairly comprehensive set of benefits, including prescription drugs. Medicaid enrollees can visit both individual care providers, and apply to be included in a Medicaid program of a private health insurance company or a managed care organization, such as for example Kaiser Permanente. However, many enrollees have difficulty finding providers (especially physicians) that accept Medicaid due to its low reimbursement rate.

**US department of Veteran Affairs Administration** is a federally administered program for veterans of the military. Healthcare is delivered in government-owned VAA hospitals and clinics. The VA is funded by taxpayers and generally very affordable, if not free for the about 20 million US veterans.

**The Military Health System (MHS)** is an enterprise within the United States Department of Defense. With a \$50 billion budget, MHS provides healthcare to about 10 million active duty and retired U.S. Military personnel and their dependents. MHS employs more than 137,000 in 65 hospitals, 412 clinics, and 414 dental clinics, as well as in contingency and combat-theater operations worldwide. Currently, MHS has a bid out for an estimated \$11 billion worth Healthcare Management Systems Modernization contract. The plan is for initial operating capabilities by 2017.

Only a minority (30%) of the United States population is covered by the public financing system – mainly Medicare and Medicaid. Currently, the majority of Americans (54%) receive their coverage from private health insurance.

**Employer-sponsored private health insurance** represents the main way in which Americans receive health insurance. Insurance packages are administered by private companies. Employers and employee pay each their part of the premium. Benefits vary widely with the specific health insurance plan, as do the rate of cost-sharing. As healthcare costs have risen in the US, employers have shifted more costs onto employees. There are significant user charges associated with private insurance. The average premium cost of employer-based single coverage was \$5049 in 2010, 18 % of which was paid by the employee. In general, the trend is that as healthcare costs have risen in the US, employers have shifted more of the costs onto employees. In addition, co-payment costs have also raised considerable, and as a result, many struggle to pay medical and pharmaceuticals bills.

**Private non-group health insurance** is for part of the self-employed or retired population, in addition to some people that are unable to obtain insurance from their employer. Companies are allowed to deny people coverage based on pre-existing conditions. Plans are administered by private companies. Individuals pay an insurance premium out-of-pocket for coverage. Risk depends only on the health status of the individual. Benefits vary widely with the specific insurance plan.

Purchasers in the form of **health maintenance organizations (HMOs)** provide healthcare services on a prepaid basis through a network of providers) grew rapidly during the 1980s and early 1990s. Their market share has fallen substantially since then, due to a backlash against the tight restrictions put on patients, and **preferred provider organizations (PPOs)** have come to dominate the private insurance market. These contract with a network of providers but they tend to pay physicians on a

fee-for-service basis, and make it easier to seek care outside the network. In 2012, among insured employees, 56% were in PPOs and only 25% in HMOs or similar plans.

According to the United States Census Bureau, in 2012 there were 48.0 million **Uninsured individuals** in the US. Health services for the uninsured are often provided by a safety-net system of public and community clinics, as well as hospitals and physicians.

### **Policy debated and ongoing healthcare reform**

The Patient Protection and Affordable Care Act, more commonly referred to as the Affordable Care Act (ACA, or better known as “Obamacare”), signed into law in 2010, will result in many significant changes in the United States health-care system if it is fully implemented. The implementation dates of other provisions vary. The aim is to extend health insurance coverage to some of the estimated 15.4% of the population who were without health insurance.

The law requires all Americans to have health insurance, but offers subsidies to make coverage more affordable and aims to reduce the cost of insurance by bringing younger, healthier people into the health insurance system. It also requires businesses with more than 50 full-time employees to offer health coverage, although this provision was delayed until 2015 to allow more time for compliance. The law creates marketplaces - with websites akin to online travel and shopping sites - where individuals can compare prices as they shop for coverage. In addition, the law bans insurance companies from denying health coverage to people with pre-existing health conditions, allows young people to remain on their parents' plans until age 26, and expands eligibility for the government-run Medicaid health program for the poor. The law aims eventually to slow the growth of US healthcare spending, which is the highest in the world.

The reform is hugely contested by the Republican Party, claiming that the law imposes too many costs on business, and that it is an unwarranted intrusion into the affairs of private businesses and individuals. As a result, the phased rollout of the law has been marked by setbacks.

Given the extensive use of PPO plans, it is not uncommon that many healthcare providers service different parts of one patient's healthcare needs. Often the care delivered is not coordinated across providers creating inefficiencies, increasing costs and reducing quality. As a response, we see the establishment of **Accountable Care Organizations (ACOs)**, health-care providers that may be independent organizations but work in concert to improve patients' health and reduce costs. These organizations may, for example, share a patient's medical records to ensure that care is coordinated, duplication of services and tests is avoided, and that prescription drug interactions are not harmful.

Overall, coordination of care, and system interoperability is a key challenge for the US healthcare system. The ACA mandates large shifts in the IT infrastructure of healthcare. A central criticism of the US healthcare system for many decades has been its high variability and inconsistency.<sup>101</sup> A key

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<sup>101</sup> In the late 1990s, the President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry found that “in America there is no guarantee that any individual will receive high-quality care for any particular health problem. The healthcare industry is plagued with overutilization of services,

objective for the use of ICT in health is to be able to provide care that meets their needs and is based on the best scientific knowledge. Another central aim is to stimulate digitization and interoperability, in order to enable better coordination of care across the network of service providers and which oversees the different elements of an individual's healthcare.

In the following, we shall take a closer look at how the drive for better quality is part of the current US national eHealth strategy.

### ***11.5 eHealth in USA: Past, Present and Future***

#### ***Timeline***

**2004:** As deployment of IT in various sectors of the US economy was advancing, the Bush administration signed two Executive Orders that launched an effort to promote the adoption of EHRs nationwide. The plan sought to ensure that most Americans would have EHRs within 10 years, although it did not allocate federal funding to reach that goal.

The same year, [the National Coordinator for Health Information Technology \(ONC\)](#) is established. ONC is the principal federal entity charged with coordination of nationwide efforts to implement and use certified health information technology and promotes the adoption of national standards and the interoperable exchange of health information.

ONC funds development projects for Nationwide Health Information Network (NHIN). NHIN is a set of standards, services and policies that enable secure health information exchange over the Internet. Several components form the basis of the NHIN - authentication and certification, vocabulary and message standards, delivery protocols, directories, a trust framework and security. The NHIN is not a single health information exchange model, but a combination of four different components that can be used together or separately to enable HIE activity over the Internet:

**NHIN Gateway Specification:** a description of the standards, services, and policies needed to exchange information over the Internet.

**Federal Health Architecture Connect Software:** the computer code based on the gateway specification that can be installed on provider systems and used to exchange information.

**NHIN Exchange:** a network of federal agencies including the Department of Defense, Social Security Administration, and Centers for Disease Control and Prevention that use Connect software to exchange health information. The entities all signed a user agreement known by its initials, DURSA, which provides a legal, privacy, and security framework for the exchange. It is the NHIN Exchange that could be expanded to healthcare facilities, creating a nationwide health information exchange.

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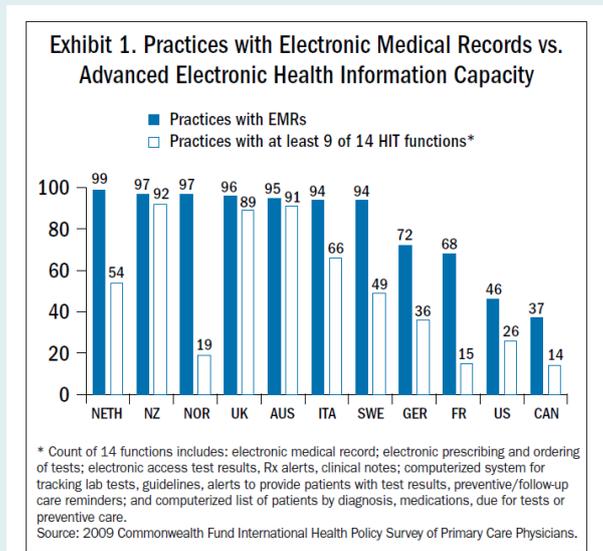
underutilization of services, and errors in healthcare practice.” In 2003, McGlynn et al quantified many of the quality deficiencies in the healthcare delivery system. Evaluating quality measures for 30 acute and chronic conditions, the authors found that patients received recommended care only 54.9% of the time.

**NHIN Direct:** a stripped-down version of the Connect software that will enable a simple one-to-one exchange of basic information between providers.

**2008:** The first Federal Health IT Strategic Plan was published in June 2008.

**2009:** [HITECH Act](#) provides HHS with the authority to establish programs to enable the implementation of a nationwide health information technology infrastructure. The infrastructure should improve healthcare quality, safety, and efficiency through the promotion of health IT, including EHRs and private and secure electronic health information exchange. At the current time, US is lagging behind other countries in the deployment of EHR systems (see figure 33).

**Figure 34. Practices with EMRs vs Advanced EHR capacity**



Source: *The Commonwealth Fund 2012*

As part of the American Recovery and Reinvestment Act of 2009 - the Obama Administration's economic stimulus package - the federal government allocates \$27 billion over 10 years to promote the adoption and use of EHRs.<sup>102</sup> Financial incentives are made available to eligible providers meeting a set of specific criteria [meaningful use](#) of EHRs. 5 years of financial incentives, up to a maximum of \$44,000 per Medicare-eligible professional and \$63,750 per Medicaid-eligible professional, plus 4 years of incentives for eligible hospitals. In 2015, the carrot becomes a stick for providers, as Medicare reimbursements will be adjusted downwards for those who do not demonstrate meaningful use of certified EHR technology.

The purpose of the meaningful use model is to secure development and use of certified EHR technology for the promotion of **quality, patient safety, efficiency** and **equity** of healthcare. What is

<sup>102</sup> EHR is defined as information exchanges across enterprises not only the local EMR system.

more, the aim is to engage patients and their kin in health and care, support coordination of care, promote preventive work and public health, and handle privacy and information security issues.

The regulative model shall help vendors assure that their systems adhere to existing standards for functionality. The model shall also contribute to that healthcare providers make sure that the EHR system that they procure will ensure meaningful use, in accordance with national priorities objectives for adoption and use of EHRs. Qualified healthcare providers who adhere to the standards for meaningful use (uses certified EHR technology in order to achieve specific objectives) are eligible for Medicare and Medicaid incentive payments.

[The Health Information Technology Policy Committee \(HITPC\)](#) advises the HHS on federal health IT issues, including how to define Meaningful use.

The Meaningful use roadmap three phases of iterative standard development and deployment.

- **Stage I (2011)** included some of the basic requirements essential for creating any medical record—for example, the ability to record patient demographic information and vital signs, up-to-date problem lists (current and active diagnoses), current medications and allergies, and smoking status. The focus is on coded data- capture, storage, collection, and reporting by multiple departments *within* an enterprise. Important functional objectives are use of information to track clinical conditions and communicate the information in order to support coordination of care.
- **Stage II (2013)** seeks to align the incentives for using EHRs with the key priorities of the National Quality and focuses on information sharing and quality improvement at the point of care. Important functional objectives are support of continuous quality improvement in clinical practice and information exchange across enterprises, locations and HER systems.
- **Stage III (2015) focuses on** decision support for nationally prioritized diagnosis. Important functional objectives are promotion of quality improvement, patient safety and efficiency.

**2010:** ONC launches [the State HIE Cooperative Agreement Program](#), which funds states' efforts to rapidly build capacity for exchanging health information across the healthcare system both within and across states. Awardees are responsible for increasing connectivity and enabling patient-centric information flow to improve the quality and efficiency of care. Key to this is the continual evolution and advancement of necessary governance, policies, technical services, business operations, and financing mechanisms for HIE. The program builds on existing efforts to advance regional and state-level health information exchange while moving toward nationwide interoperability. Further funding for HIE provided by the 2011 [State HIE Cooperative Agreement Program](#).<sup>103</sup> The aim is to standardize:

- *meaning* through the use of standardized healthcare vocabularies
- *structure* by leveraging standards in HL7

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<sup>103</sup> There are several studies pointing to the lack of actual deployment of both HER systems and HIE solutions in the US healthcare system. See for instance: <http://www.ncbi.nlm.nih.gov/pubmed/22084896>

- *transport* using secure email protocols
- *security* through National Institute of Standards and Technology (NIST)-adopted encryption standards
- *services* through open, and accessible application programming interfaces (APIs)

There are currently three key forms of HIE for which the foundation of standards, policies and technology required to initiate all three forms of health information exchange are complete, tested, and available today:

- Directed Exchange – ability to send and receive secure information electronically between care providers to support coordinated care.
- Query-based Exchange – ability for providers to find and/or request information on a patient from other providers, often used for unplanned care.
- Consumer Mediated Exchange – ability for patients to aggregate and control the use of their health information among providers.

January 2010, VA and KP connect VistA and KP HealthConnect to exchange patient information about diagnoses, medications and allergies using NHIN.

**2011:** ONC releases [Federal Health Information Technology Strategic Plan 2011 – 2015](#)

**2014:** Two key documents are released this year, one focusing on interoperability, the other on Quality improvement. Both documents build on an acknowledgment of the contextual changes since the 2011 strategic plan. In the wake of the HITECH Act and the EHR incentive program, the health IT ecosystem has undergone radical transformation.<sup>104</sup>

- All 50 states have some form of health information exchange services available to support coordination of care.
- 50 % of hospitals are able to electronically search for patient information from sources beyond their organization or health system.
- A national product testing and certification program has been established to certify meaningful use.
- More than 50 % of office-based professionals and more than 8 out of 10 hospitals are meaningfully using electronic health records (EHRs)
- The industry of consumer health technologies is growing rapidly and advancing care models and consumer engagement.

Opportunities for improvement are identified as (list not exhaustive):

- Increased adoption of health IT by providers and facilities that have not received incentives for EHR adoption to date.

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<sup>104</sup> <http://www.healthit.gov/buzz-blog/from-the-onc-desk/report-congress-progress-ehr-adoption/>

- Usability and clinician workflow improvements necessary to ensure that health IT is optimized to support safe and enhanced care quality.
- Lack of data interoperability across EHR systems remains a substantial barrier to health information exchange and support of quality improvement efforts.

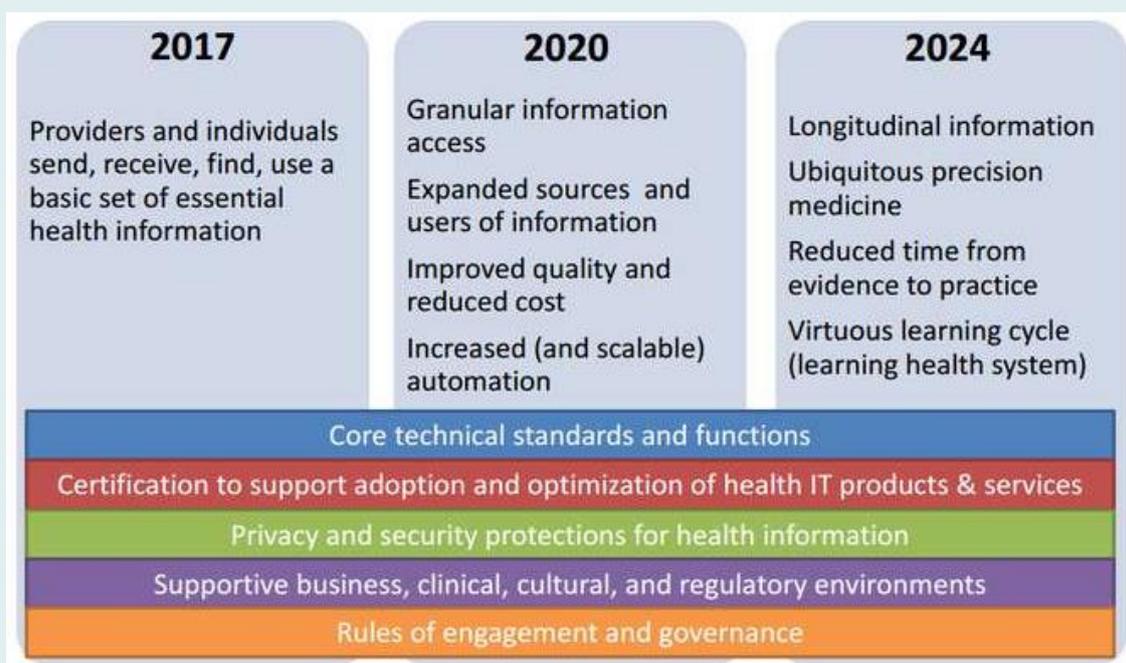
In June 2014, ONC published [Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure](#). The following principles for developing an interoperable national eHealth system are singled out:

- **Build upon the existing health IT infrastructure**, increasing interoperability and functionality as needed.
- **One size does not fit all.** Strive for baseline interoperability across health IT infrastructure, while allowing local variation (the feel and function of tools) in order to best meet the user's needs based on the scenario at hand, technology available, workflow design, personal preferences, etc.
- **Use Health information to empower individuals** to become more active partners in their health.
- **Leverage the market.** As payment and care delivery reform increase demand for interoperability, we will work with and support these efforts.
- **Simple solutions first**, allowing for more complex methods in the future.
- **Maintain modularity to secure** resilience for innovation and adoption of new, improved technological and medical approaches over time without overhauling entire systems.
- **Account for a range of capabilities among information sources and information users, and support multiple levels of advancement.** Individuals and caregivers have an ongoing need to find, send, receive, and use their own health information both within and outside the care delivery system and interoperable infrastructure should enable this.
- **Focus on value** to individuals and care providers; improved health, healthcare, and lower costs should be measurable over time and at a minimum, offset the resource investment.
- **Protect privacy and security in all aspects of interoperability.**

The aim is to develop a shared agenda that focuses on five critical building blocks for a nationwide interoperable health information infrastructure:

1. Core technical standards and functions
2. Certification to support adoption and optimization of health IT products and services
3. Privacy and security protections for health information
4. Supportive business, clinical, cultural, and regulatory environments
5. Rules of engagement and governance

Figure 35. Interoperability Roadmap vision and building blocks



Source: ONC

Building on the interoperability vision paper, an [interoperability roadmap](#) was published in June 2014. Taking five critical building blocks as a starting point (see figure 34, within each of them, the roadmap describes functional and business requirements for a learning health system and the associated actions for making rapid near term progress.

In November 2014, ONC publishes [Health IT Enabled Quality Improvement: A Vision to Achieve Better Health and Healthcare](#). The report describes a vision for an electronically enabled quality improvement (QI) ecosystem that promotes better health and care, improved communication and transparency, rapid translation of knowledge for all stakeholders and reduction in the burden of data collection and reporting for providers.

The aim for the interoperable health IT QI ecosystem is to make the right information available to the right people at the right times, across products and organizations, to help individuals make fully informed decisions about their health and healthcare and to help healthcare providers deliver safe, effective care. Providers, patients and researchers will have the complete health and clinical picture and benefit from personalized options informed by rich and malleable data that can provide numerous types of health IT enabled decision-making, quality monitoring and real-time and predictive analytics.

CMS and many private payers are committed to payment models that reward quality and efficiency, incentivizing better outcomes and lower costs. Presently, a very small percentage of payments by CMS are strictly fee-for-service. Nearly all CMS payment models have a link to quality, whether through the fee for service system, an alternate payment model or global population-based payment models. In order to be successful in these new payment environments, providers must invest in

delivery system re-design which includes more robust leveraging of health information technology and interoperability.

A number of quality reporting systems are in place in the US, mainly for hospitals. These include quality reports required by the federal government and voluntary reports for private organizations. The manner in which data for these quality reports are gathered varies. If the provider does not have an EHR, data is collected by risk management or quality improvement departments. Some data can be extracted from the patients' administrative records submitted to the CMS for payment of care, where as other data are obtained through chart reviews, incident reports or patient records. The data must be manually entered into electronic databases. As quality reporting is becoming a requirement for payment by CMS, the pull for interoperable EHR solutions increase.

Interoperability standards to support QI are evolving to be better aligned. Standards for specifying and reporting CQMs from EHRs are in use, but these standards are complex, evolving and difficult to implement and often require extensive implementation guidance for each measure. As such, quality measure specifications are implemented inconsistently at the local level and are not comparable across providers and settings of care.

The shift to value-based payment and accountable care is creating a need for new longitudinal measures of quality and health outcomes across settings of care; this will require new health IT solutions beyond EHRs and intermediaries that will aggregate data, report measures and provide actionable feedback to providers in a rapid cycle fashion.

The strategy is to take two hitherto parallel communities of practice in US healthcare - Quality CDS (Clinical Decision Support) and CQM (Clinical Quality Measures) – and join these into one joint effort aligned focus of quality improvement: CQI – Clinical Quality Improvement.

- Use the same technical standards
- Strategically use certification and testing to assure users that improvement tools do what they need to do;
- Incorporate the same strong privacy and security protections for individuals' health information;
- Foster business, clinical, and regulatory environments that support **both** the development of effective, user-friendly quality improvement tools **and** the appropriate exchange and use of health information to support easy use of those tools; and
- Develop rules of engagement and governance that facilitate availability and use of quality improvement functions and the information on which they will rely.

Health IT will provide the necessary tools to achieve this vision through an interoperable infrastructure and supportive building block such as:

- Rapid translation of research, evidence, or best practices into electronically actionable guidelines that enable decision support, quality measurement and reporting.
- Capturing healthcare data in a structured way. Using data elements consistently and reliably will allow for information to be collected once and reused for multiple purposes.
- Valid, reliable and accurate patient outcome measures that support risk-adjustment analysis and are comparable across settings and payers.

- Robust and real-time analytical tools for routine, practice level and ad-hoc measurement.
- Interoperable and easy to use tools that leverage/collect the existing data for multiple QI reporting programs.
- Data must follow the individual.

Development and implementation of these QI ecosystem building blocks shall create a rapid and actionable feedback loop to continually update science and refine the specificity and usability of the knowledge while making healthcare safer, more effective and more affordable.

**2015:** Updated [Federal Health IT Strategic Plan \(2015-2020\)](#) released by ONC. Work towards more widespread adoption of health IT will continue, while efforts will begin to include interoperability between systems and inclusion of new sources of information, and use of decision support systems for the dissemination of knowledge into clinical practice.

**Figure 36. Policy Goals and Objectives in Current US Federal eHealth Strategy**

	Goal	Objective
Collect	Goal 1: Expand Adoption of Health IT	<ul style="list-style-type: none"> <li>• Objective A: Increase the adoption and effective use of health IT products, systems, and services</li> <li>• Objective B: Increase user and market confidence in the safety and safe use of health IT products, systems, and services</li> <li>• Objective C: Advance a national communications infrastructure that supports health, safety, and care delivery</li> </ul>
	Goal 2: Advance Secure and Interoperable Health Information	<ul style="list-style-type: none"> <li>• Objective A: Enable individuals, providers, and public health entities to securely send, receive, find, and use electronic health information</li> <li>• Objective B: Identify, prioritize, and advance technical standards to support secure and interoperable health information</li> <li>• Objective C: Protect the privacy and security of health information</li> </ul>
Use	Goal 3: Strengthen Health Care Delivery	<ul style="list-style-type: none"> <li>• Objective A: Improve health care quality, access, and experience through safe, timely, effective, efficient, equitable, and person-centered care</li> <li>• Objective B: Support the delivery of high-value health care</li> <li>• Objective C: Improve clinical and community services and population health</li> </ul>
	Goal 4: Advance the Health and Well-Being of Individuals and Communities	<ul style="list-style-type: none"> <li>• Objective A: Empower individual, family, and caregiver health management and engagement</li> <li>• Objective B: Protect and promote public health and healthy, resilient communities</li> </ul>
	Goal 5: Advance Research, Scientific Knowledge, and Innovation	<ul style="list-style-type: none"> <li>• Objective A: Increase access to and usability of high-quality electronic health information and services</li> <li>• Objective B: Accelerate the development and commercialization of innovative technologies and solutions</li> <li>• Objective C: Invest, disseminate, and translate research on how health IT can improve health and care delivery</li> </ul>

Source: ONC

The Plan describes the governments strategies to achieve five goals (see figure 35), of which the first two increasing the electronic collection and sharing of health information, and the three final goals focus on federal efforts to create an environment where interoperable information is used by the healthcare sector to improve care and reduce costs. The Plan is currently open for formal public comments, and a final version will be launched in 2015.

The organization of the US healthcare system, with several large organizations offering comprehensive services for large portions of the population makes it interesting to look more closely at how ICT is being put to use in these organizations. While the US, as a country, is lagging behind in eHealth deployment,<sup>105</sup> we also find some of the most advanced EHR systems in the world in the US. In the following we shall look at two of those systems, Kaiser Permanente - HealthConnect and the Veteran Affairs Administration - Vista.

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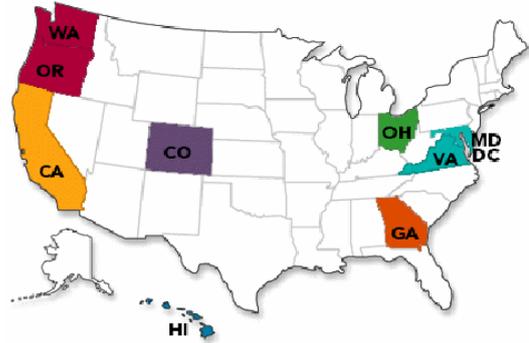
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[http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2011/Nov/1565\\_Gray\\_electronic\\_med\\_records\\_meaningful\\_use\\_intl\\_brief.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2011/Nov/1565_Gray_electronic_med_records_meaningful_use_intl_brief.pdf)

## 12 Kaiser Permanente – HealthConnect

### 12.1 About Kaiser Permanente

Founded in 1945, Kaiser Permanente (KP) is one of the largest integrated healthcare organizations in the United States, serving more than 9 million members across eight regions: Northern California, Southern California, Northern Colorado, Southern Colorado, Georgia, Mid-Atlantic (Maryland, Virginia and Washington DC), Northwest (Oregon and Washington) and Ohio.



KP consists of three organizational entities:

- **Kaiser Foundation Health Plans** is a non-profit corporation that contacts with individuals and groups to arrange comprehensive medical and hospital services for a fixed monthly fee.
- **37 Kaiser Foundation Hospitals** and their subsidiaries, which own and operate hospitals as well as medical centers and outpatient facilities.
- More than **420 Permanente Medical Groups** which provides multispecialty healthcare services to members of KP health plans in the eight KP regions. The groups assume full responsibility for providing and arranging necessary medical care in each region.

As a HMO, KP provides all elements of healthcare, including hospitals, clinics, Labs, pharmacies, image centers, home nursing, and nursing homes KP employs 180.000 workers and has annual revenue of \$50 billion dollars.

The regional medical groups are physician-owned and exclusively contract to provide medical services to the KP members. Each of the medical groups operates as an independent, separate, for profit partnership or professional corporation in its individual region and receives nearly all of its funding from its respective Kaiser Foundation Health Plan.

The hospital foundations are not-for-profit and rely on the Kaiser Foundation Health Plan for funding, and they provide infrastructure and facilities that benefit the medical groups.

KP both pay for and deliver care, there is a strong incentive to work preventively in order to keep people healthy and effectively managing illnesses. The integration of finance and care delivery services creates the ability to allocate resources where needed to achieve the best health outcomes for the patient. KP's pre-paid payment model and integrated structure place as much emphasis on keeping people healthy as it does on providing treatment for members when they are ill.

### 12.2 The HealthConnect project

Towards the end of the 1990s, KP was facing increasing competition in the healthcare and needed to take action to differentiate itself and improve competitiveness. In 2002, a 10-year, \$3 billion capital investment (which grew to more than \$4 billion) strategic investment was made to buy a shared HER system for the enterprise - KP HealthConnect.

Figure 37. Aims for Organization Reform

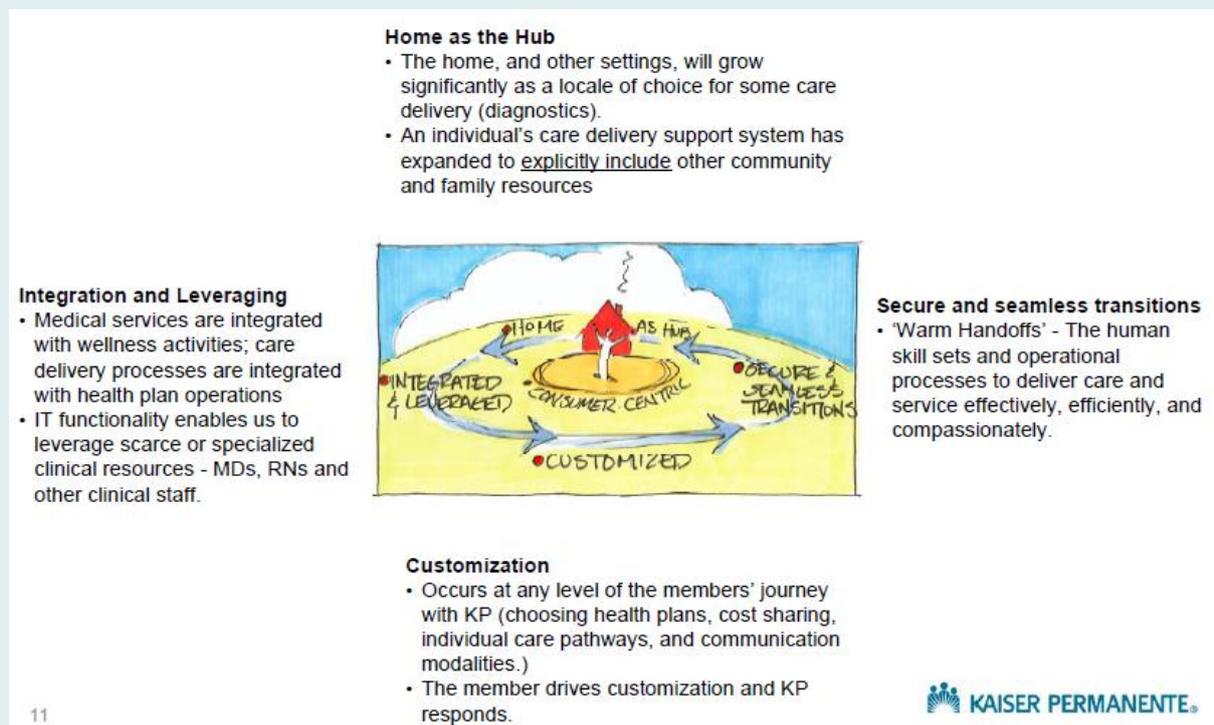
Quality Our Patients Can Trust	Personal & Convenient Service	Affordable Health Care
<p><b>High Quality</b></p> <ul style="list-style-type: none"> <li>• We have clinical information available 24/7.</li> <li>• Our clinical outcomes are unsurpassed.</li> <li>• Our clinicians know in real-time the recommended best practices.</li> <li>• We are the national leaders in patient safety.</li> <li>• We enhance our research to support evidence-based care.</li> </ul>	<p><b>Personal</b></p> <ul style="list-style-type: none"> <li>• We have and use up-to-date clinical, social and patient preference information.</li> <li>• We provide patients information for shared decision making.</li> <li>• We enhance personalized care.</li> </ul> <p><b>Convenient</b></p> <ul style="list-style-type: none"> <li>• Our patients access information via telephone, Web and email.</li> <li>• We actively support our patients' participation in their own care.</li> <li>• We minimize wait times and out-of-pocket costs with efficient access to care.</li> <li>• We achieve superior integration and continuity of care.</li> </ul>	<p><b>Affordable</b></p> <ul style="list-style-type: none"> <li>• We reduce the cost of care and improve visit experiences.</li> <li>• We eliminate waste associated with paper medical records and missing medical records.</li> <li>• We eliminate costly in-person services unless medically necessary or desired by the patient.</li> <li>• We streamline IT and administrative processes and costs</li> </ul>

Source: KP

The project was based on a desire to transform the overall quality of healthcare delivery across KP. HealthConnect built on a much broader strategy for patient-centered care. Prior to the development of KP Health Connect, an organizational vision for healthcare was drawn up, to guide the development of an information system - the "Blue Sky Vision" (see figure 37). The Blue Sky Vision created a future conception of the implementation and use of KP HealthConnect which united leaders, clinical teams and system users alike around a common goal: *"All The Data, About All The Patients, All The Time"*.

Guided by the Blue Sky Vision, the HealthConnect project was approached as a strategic investment to transform healthcare delivery, rather than as an IT-project.

Figure 38. The Blue Sky Vision



Sources: Kaiser Permanente

The KP executive board designated the HealthConnect project the number one priority in the business plan for three years. This meant that executive compensation was tied to the achievement of development and deployment milestones. Progress was reported to the board quarterly, and progress against plan was a condition for other capital expenditures, such as new facilities.

Common system elements were developed on a national collaborative basis, while additional regional choices were made to reflect local workflows. Clinician involvement was considered critical in designing the system. Doctors, nurses, clinical experts, key business stakeholders and IT experts from all branches of the organization worked together to figure out how to customize the product for KP's specific needs and identify what features and functions could best serve its members. Beyond thinking about how the technology should work, these professionals and experts also helped change some of KP's operational processes and procedures to make sure that the organization's technology and services would work well together.

KP HealthConnect was not to be seen as an IT project, but one that was jointly managed between operational leaders and the IT function. Once the national leadership team was in place, each region created its own project team, with senior leaders named as key sponsors to drive the implementation forward. Collaboration between clinical professionals and management is particularly essential to establish successful process for learning from both successes and challenges.

The conversion to KP HealthConnect had a major impact on the daily work of physicians, clinicians and other staff. The transition was a culture shock for many. Many found that the additional coding and documentation required to use KP HealthConnect took away time they had previously spent with patients, while some struggled with using the system itself. Hence, a large portion of the

deployment costs (perhaps two-thirds) was dedicated to training and workflow redesign along with communication and change management. Leaders worked hard to establish a culture in which patients and professionals collaborate to improve health. Skill gaps were identified and clinicians received targeted individual training from a user proficiency program. KP used a range of training tools at implementation and on an ongoing basis, including self-service training opportunities, crash courses, workflow analysis and more.

KP took a collaborative approach to data governance, by establishing broad communities of interest in each information domain to determine the degree of data standardization. The extensive involvement of healthcare personnel in the decision making process was considered a key factor to the success of the project. What is more, workflows and technology is continuously subject to reconfigurations in the ongoing process of innovating care.<sup>106</sup>

Flexibility and innovation at the local level is seen as essential. KP was successful in reaching a balance between a nationally mandated initiative and the need to allow for local flexibility, experimentation and innovation. The result is that health teams are able to take a more active role in healthcare delivery improvement and system reconfiguration.

The journey, from the decision to implement, through pre-planning and implementation spanned approximately seven years. Assessing the value of the HealthConnect, Dr. Andy Wiesenthal, Associate Executive Director of the Permanente Foundation, points out that the investments in ICT outweighs efficiency gains following for instance reduced duplicate office visits and tests. Also because technology that can perform even more advanced analysis of records, helping doctors make better treatment decisions—and make patients healthier. Gains are seen in terms of increasing life rates, and patients who live longer may ultimately end up consuming greater health-care resources: "We like what we get for the money but we're not going to save any money, nobody is going to save any money."<sup>107</sup>

As HMO, KP differs from PPOs in that KP owns the hospitals, pharmacies, and labs, but also because the physicians in the Permanente Medical Groups only see patients insured by KP.<sup>108</sup> Unlike most physicians, who are paid by the office visit or procedure, KP doctors are paid salaries. This is an important distinction because KP as an organization carries the costs of implementing the system and has the power to mandate that doctors use it.<sup>109</sup>

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<sup>106</sup> See for instance <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3613027/> for a description of the ongoing reconfigurations following the HealthConnect implementation phase.

<sup>107</sup> [http://www.bloomberg.com/bw/technology/content/apr2009/tc2009047\\_562738.htm](http://www.bloomberg.com/bw/technology/content/apr2009/tc2009047_562738.htm)

<sup>108</sup> KP also offer services to Medicaid and Medicare patients, given that reimbursement for services offered within these programs are conditioned by adherence to Meaningful use regime, also for healthcare providers offering services to this patient group it would be a strong

<sup>109</sup><sup>109</sup> [http://www.bloomberg.com/bw/technology/content/apr2009/tc2009047\\_562738.htm](http://www.bloomberg.com/bw/technology/content/apr2009/tc2009047_562738.htm)

### **Timeline**

**1997:** KP had numerous disparate IT systems, limited standard data elements, expensive IT maintenance costs, and largely paper-based medical records. A national clinical information system is established as a corporate goal of KP. Nine semi-autonomous entities—eight regions, each with their own strategies, budgets, culture, work processes and needs, and the national level organization—is to move into a single, patient-centered system.

**1999:** Joint development with IBM and initial deployment of a nationwide clinical information system (CIS). The CIS addressed only the outpatient medical office, not the whole enterprise. Nonetheless, the project is delayed, fails to keep pace with technological developments, and overruns budget before it achieves widespread implementation.

**2002:** Terminates CIS project after having spent more than \$400 million and launch a re-assessment process regarding organizational ICT strategy. Key questions are:

- Buy versus build - Decided to buy from vendor on the grounds that -
  - CIS strategy was risky and expensive
  - Needed a much broader integrated applications portfolio including outpatient, inpatient and practice management, web interface for members and providers, reporting capability
  - Ten-year costs were substantially less than a build and maintain strategy
  - Total involvement converted
- Suite versus best of breed
- Single instance of entire program versus multiple instances to be synchronized
- What are our clinical/operational goals? The Blue Sky Vision process is initiated to draw up a shared organizational strategy for the future use of ICT in health.

**2003:** License American ICT vendor Epic, to use their EHR system as the technological base for KP HealthConnect. System capabilities needed to:

- Share data and move information across 18 instances in 8 regions real time
- Provide a consistent data model to populate a national data repository to support all reporting needs
- Reduce variation and provide evidenced-based clinical decision support and documentation
- Share successful work practices across the country to streamline internal processes and reduce work variation

KP publishes **Blue Sky Vision**. The strategic planning outlined in the report laid the framework for using technology and service transformation to create a care delivery model that was more quality driven and patient centric.

**2005:** Launch the **21<sup>st</sup> Century Care Innovation Project**<sup>110</sup> which purpose is to leverage the use of KP HealthConnect to transform care and create thriving physician practices. The aim is to change the way work is done, instead of just focusing on efficiency. The design of a new primary care model takes the Blue Sky Vision as its starting point. Chronic care patient and patient with multiple health conditions had been identified as creating the major costs of care. Putting effort on developing coherent services for these patient groups is considered important in order to make a real difference in care and costs. The result is a focus on team based care, changes included:

- Re-designing work flows and building care team.
- Developing relationship-based care, for instance, by completing after-visit summaries (AVS) giving the patient access to medical information and latest visit instructions.
- Providing alternatives to traditional office visits by, for example, offering telephone visits and group visits and using secure messaging.
- Creating total patient panel ownership by, for example, conducting outreach to patients with chronic conditions and following up with patients on new medicines.
- Engaging members in collaborative care planning by, for example, using goal sheets with diabetic patients or convening chronic care support groups.

**2010:** Regional roll-out of HealthConnect is completed. Planning and design of inter-regional data exchange beings.

KP HealthConnect is among the world's largest deployments of an EHR System which combines tools, resources, processes and workflows working together in an integrated environment to deliver healthcare. The HealthConnect case has achieved wide recognition as an example of the successful development of an integrated EHR system.<sup>111</sup> In particular, interest has focused on the ability to couple use ICT systems to support evidence based care. In the following we shall take a closer look at the different components and services that make up the system, and some examples of how it is being used in the organization.

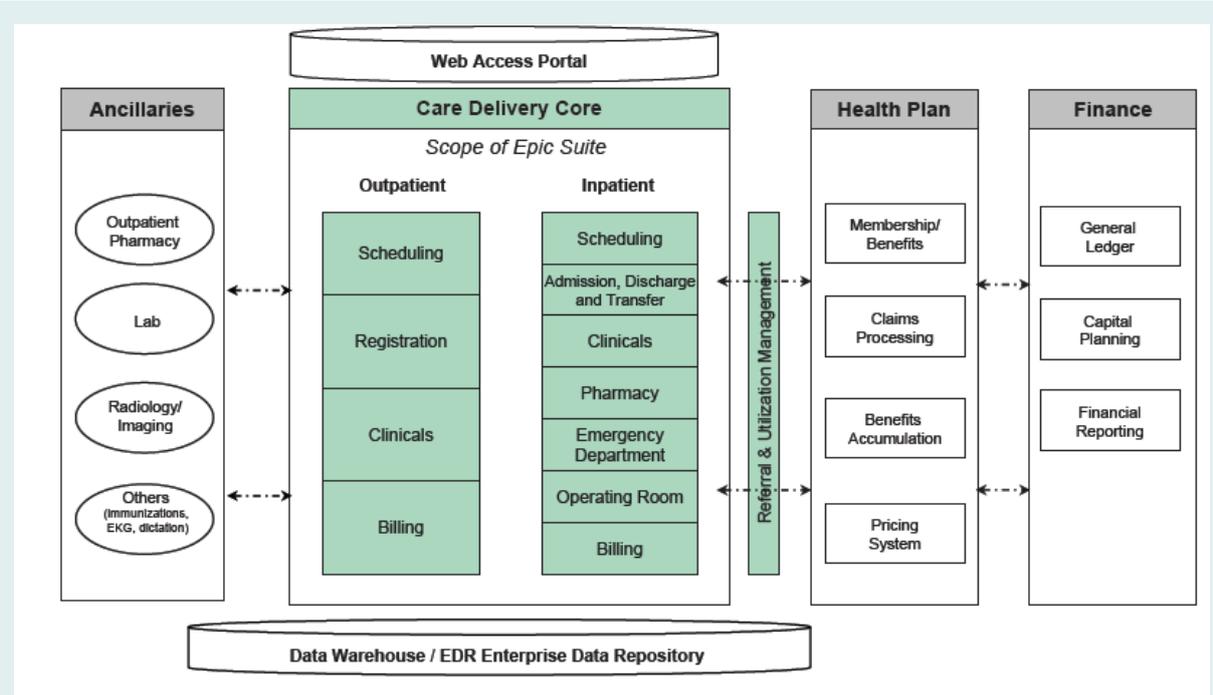
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<sup>110</sup> For more information about the project, please visit: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3061379/>

<sup>111</sup> See for instance <http://www.himss.eu/sites/default/files/Accenture-Connected-Health-Global-Report-Final-Web.pdf> and <http://hitconsultant.net/2015/01/22/himss-analytics-kaiser-permanente-system-stage-7-ambulatory-award/>

## 12.2.1 Infrastructure

Figure 39. Architecture Drawing KP HealthConnect

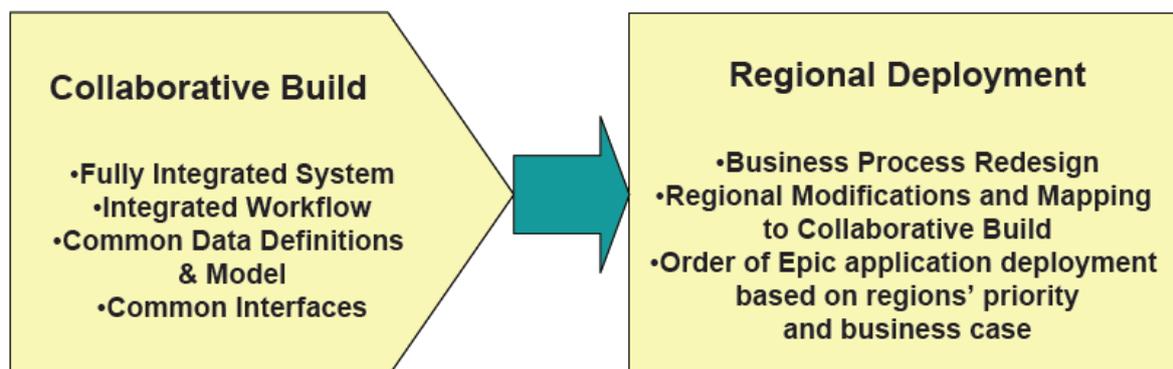


Source: Kaiser Permanente

KP HealthConnect is built according to an end-to-end SOA architecture.<sup>112</sup> The move to a common IT platform required significant IT infrastructure upgrades and high level of cross-regional collaboration. To accommodate this massive organizational change, flexibility was key to HealthConnect's design and implementation across the eight regions. KP developed a common data structure and a core set of collaborative clinical content at the outset, while regions worked together to synchronize implementations according to their strategic priorities and operational constraints. This federated approach to IT infrastructure support is still in effect today.

<sup>112</sup> [http://www.omg.org/news/meetings/workshops/SOA-HC/presentations-10/12\\_E5\\_Ferguson.pdf](http://www.omg.org/news/meetings/workshops/SOA-HC/presentations-10/12_E5_Ferguson.pdf). There are also multiple sources to the KP HealthConnect story available through KP website: <http://www.ncbi.nlm.nih.gov/pmc/?term=healthconnect>

Figure 40. KPs' Federal approach to IT infrastructure



Source: Kaiser Permanente

Three major mechanisms for health data sharing is applied throughout KP HealthConnect.

- 1) [Nationwide Health Information Network \(NHIN\)](#) — a set of federal standards, services, and policies that enable the secure exchange of health information over the Internet which was developed by the US Department of Health and Human Services Office of the National Coordinator (ONC). The NHIN is not a physical network that runs on servers at the U.S. Department of Health & Human Services, nor is it a large network that stores patient records. NHIN provides a technology “gateway” to support standards and a legal framework for the secure exchange of health information. NHIN Direct offers standardized transport specifications only, using secure e-mail technology for direct unstructured data communications among small offices such as those with <3 physicians.
- 2) Proprietary, Vendor-Specific Data Exchange Mechanisms: EpicCare
- 3) Personal Health Records and Related Modalities: Examples: Microsoft, Google, Media including USB drives

### 12.2.2 Infostructure

KP HealthConnect meets national and international standards for the transmittal and storage of health data, HL7, SNOMED-CT, LOINC, RXNORM, NIC, NOC, NANDA, DICOM, etc.

As part of what was called the “collaborative build,” KP held design-build-validate sessions with national and regional teams to standardizing data formats and medical terminology across the eight regions, to ensure that KP could leverage the data to evaluate performance and identify best practices.

Today, KP has a permanent national team—the Convergent Medical Terminology team—that works to improve terminology.<sup>113</sup> KP established “communities of practice” comprising physicians, nurses, pharmacists and others, based on areas of specialty or care setting, developed clinical content and determined the degree of data standardization. The team has developed the Convergent Medical Terminology (CMT) tool to cross-reference multiple clinical terminologies.

KP is actively engaged in national and international standard development organizations, including ISO, HL7, ASTM, DICOM, X12, NCPDP, NQF, others. In addition, KP is engaged in additional multi-lateral efforts to advance interoperability, namely Clinical Information Modeling Initiative (CIMI) and Care Connectivity Consortium (CCC).

### 12.2.3 Privacy, Information Security, Access Control

The national specified NHIN (see chapter on US) standards, services, and policies for secure health information exchange, such as information can only be shared among healthcare personnel in a treatment relationship with the patient, and a log is created to enable tracking of information retrieval.

During our information search, we have not been able to find more specific information about the access control system in use within the KP organization.

### 12.2.4 Shared eHealth Components and Services

KP HealthConnect was designed to provide instant and continuous real time access in several locations to medical records for clinicians, patients and designated family members. It securely connects members’ medical records across both outpatient and inpatient settings, coordinating care between the physician’s office, the hospital, radiology, laboratory and the pharmacy, and linking with existing insurance and finance systems. KP HealthConnect includes the following broad suite of applications:

- A program-wide system that integrates the clinical record with appointments, ancillary and specialty services, registration, and billing
- A complete healthcare business and management system
- A personal health record for members<sup>114</sup>
- Patient Portal
- Clinical Decision Support and Population Management
- Electronic access to test results to reduce or prevent the ordering of duplicate tests
- Fast electronic distribution of best-practices information
- Online ordering of prescriptions
- Outpatient practice management (including billing, registration, checking/scheduling).

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<sup>113</sup> [The terminology is made available through the American National Library of Medicine](#) in an attempt to stimulate rapid deployment of EHR systems throughout the country, as well as an attempt to establish a standard for interoperability between different EHR implementations,

<sup>114</sup> For more information about the different services, please see: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3104829/>

- Outpatient clinical (including e-prescribing, test ordering and results, computerized physician order entry—CPOE—referrals and clinical documentation, such as history of medical visits).
- Inpatient billing
- Inpatient pharmacy records
- Inpatient administrative systems (including admissions, discharge, transfer and an emergency department tracker)
- Inpatient clinical (including clinical documentation, CPOE, as well as modules to support specific medical specialties).
- Pre-existing applications, including outpatient pharmacy systems, inpatient and outpatient lab systems, and radiology systems)
- Secure e-mail<sup>115</sup>

### 12.2.5 Digital Services for Citizens

Enabling patient self-management is an important part of KP's vision. To this end, an online portal - [MyHealth Manager](#), gives members access to:

- Shared medical record for the patient, their family, and all members of their care team
- Online after-visit summaries that remind them of their doctor's instructions and comments
- Secure e-messaging to healthcare providers' offices
- Access to lab test results
- Access to a comprehensive list of their immunizations and allergies
- Online booking
- Online self-service medication e-refills
- An online health risk assessment and customized feedback, including tailored behavioral change programs
- General health and well-being information
- General health assessment tools and educational modules for different diseases and conditions
- 24/7 call center
- Directory of providers

### 12.2.6 Secondary Use of Data

Advances in clinical decision support were considered key to value realization from HealthConnect. KP has strong focus on evidence based care. Services include access to library of KP knowledge and best practices, including tools and templates to embed these in KP HealthConnect and give clinicians access to evidence-based recommendations and decision support at the point of care. These tools include medication-safety alerts, preventive-care reminders and online clinical guidelines.

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<sup>115</sup> Please see the following article for a description: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2232122/>

All KP regions have built clinical evidence and guidance into ordering and charting templates, such as “SmartSets” and “Order Sets.” Clinicians from all specialties, disciplines and regions are involved in the collection and ongoing refinement of the clinical content that underpins KP HealthConnect.

Some KP regions are using **Panel Support Tools (PST)** to enable clinicians to offer proactive— rather than reactive—care. PSTs are integrated with KP HealthConnect and combine clinical data from the organization with data from other systems (such as from hospital claims, ancillary tests and the membership system). A typical PST might combine clinical decision support functions, disease registries and continual performance feedback, allowing primary care teams to examine all care recommendations for individual patients, defined groups of patients or an entire panel. A report flags “care gaps” between evidence-based recommendations and delivered care, and calculates a monthly care performance rating for each provider team. The result is a strong focus on performance measuring and reporting to improve quality of care and patient safety.

Regions now generate a standard range of process and outcome measures at clinical department and the individual clinician level. A performance quality dashboard - “**The Big Q**” integrates a broad range of whole-system measures such as clinical quality, member satisfaction, patient safety and risk management into a single, comprehensive view. Building infrastructure for performance improvement and innovation created focus and capability for value realization. Developing rigorous tracking and evaluation processes enabled KP to develop, identify and adopt innovations and effective new practices from the very beginning.

KP operates one of the largest non-university research programs in the USA, and published nearly 1.000 research articles in 2012.<sup>116</sup> Researchers use the EHR information to study what interventions and systems are safest and most effective for which patients. Results are used to construct actionable clinical guidelines that deliver information at the point of care about what treatments and protocols are recommended based on analyses.

Through **the proactive office encounter (POE) program**, clinical care teams work together to identify opportunities to engage patients and improve preventive and chronic care management across the continuum of services. EHR information is being used to improve disease screening and treatment rates, which lower long-term health costs by preventing or successfully managing problems.<sup>117</sup>

The ability to transform results from research and monitoring activities into evidence based practice, is explained not by the existence of a comprehensive, integrated information system. Rather, it is the availability of analytical capabilities and resources capable of utilizing the data resources throughout the organization that explains the results.

KP promotes cross-learning among sites and regions in many ways—innovation funds and awards, site visits, learning collaborations and workshops are just some examples. System-wide resources are

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<sup>116</sup> [More information about the link between HealthConnect and in-house research activities.](#)

<sup>117</sup> [More information about the Proactive Encounter Program.](#)

available, such as those of the Care Management Institute, which convenes inter-regional working groups of clinical experts to develop evidence-based guidelines, tools such as health risk assessments and model care management programs, and investigates the causes of interregional variations to identify best practices for better patient outcomes. Local clinical champions receive resources and tools to educate and engage their colleagues in improving practice and outcomes for patients. As the organization learns from each region's experience in using KP HealthConnect, a small national team updates the KP library with new evidence of successful practices.

## 13 Veteran Health Administration (VHA)

### 13.1 About Veteran Health Administration

The Department of Veterans Affairs was established as an independent agency under the President by Executive Order in 1930. Today the Veterans Health Administration (VHA) is the largest integrated healthcare system in the US and the second largest federal department with 312,000 employees. The Department serves US Veterans and their families, and holds primary responsibility for ensuring that they receive medical care, benefits, social support, and lasting memorials promoting the health, welfare, and dignity of 8.5 million Veterans.

VA comprises a Central Office (VACO), which is located in Washington, DC, and field facilities throughout the Nation administered by its three major line organizations: the Veterans Health Administration (VHA), the Veterans Benefits Administration (VBA), and the National Cemetery Administration (NCA).

Services and benefits are provided through a nationwide network of 151 medical centers, 820 community-based outpatient clinics, 300 Vet Centers, 56 regional offices, and 131 national and 90 State or tribal cemeteries.

The VA is financed mostly from general taxations. In 2009, President Obama signed the [Veterans Healthcare Budget Reform and Transparency Act](#), legislation that shields the VHA healthcare system from the harmful effects of budget stalemates, continuing resolutions and government shutdowns. This historic law authorized advance appropriations for VHA healthcare, providing the funding one year in advance and thus avoiding the ill effects of budget brinkmanship. As a result, during a federal government shut down due to a lapse in appropriations or over a debt ceiling fight, the VA healthcare system already is funded to provide uninterrupted care to wounded, injured and ill veterans.

The Secretary of Veterans Affairs (SECVA) has identified three strategic goals for VHA to focus on as the means to improve services to Veterans and their families and to improve management in the Department. These goals are the components of the [2014-2020 VA Strategic Plan](#):

- **Strategic Goal 1:** Empower Veterans to Improve Their Well-being
- **Strategic Goal 2:** Enhance and Develop Trusted Partnerships
- **Strategic Goal 3:** Manage and Improve VHA Operations to Deliver Seamless and Integrated Support

The **Assistant Secretary for Information and Technology** serves as the Chief Information Officer (CIO) for the Department. As the CIO, the Assistant Secretary is responsible for the vision, management, operation, and execution of VA's Office of Information and Technology (OIT) and its resources, delivering adaptable, secure and cost effective technology services to the Department.

[The Office of Information and Technology \(OI&T\)](#) provides strategic and technical direction, guidance, and policy to ensure that the Department of Veterans Affairs' IT resources are acquired and managed in a manner that abides by Federal laws and regulations. OI&T delivers available, adaptable, secure, and cost-effective technology to VA and acts as a steward for most of VA's IT assets and resources. OI&T strives to provide innovative tools that enable excellent customer service. OI&T is led by the

Executive in Charge and Chief Information Officer, and is composed of eight organizational elements: DoD/VA Interagency Program Office (IPO); the Office of Quality, Performance, and Oversight (QPO); Architecture, Strategy, and Design (ASD); the Office of Customer Advocacy; IT Resource Management (ITRM); the Office of Information Security (OIS); Product Development (PD); and the Office of Service Delivery and Engineering (SDE).

[DoD/VA Interagency Program Office](#) acts as the single point of accountability in the development and implementation of electronic health records (EHR) systems or capabilities that allow for full interoperability of healthcare information between the Departments. To further this purpose, the DoD/VA IPO leads the Departments' efforts to implement national health data standards for interoperability and is responsible for establishing, monitoring, and approving the clinical and technical standards profile and processes to ensure seamless integration of health data among the two Departments and private healthcare providers.

By the early 1990s, the VA had a reputation for delivering limited, poor-quality care, which led to healthcare reforms. By 2000, the VA had substantially improved in terms of numerous indicators of process quality and some evidence shows that its overall performance started exceeding that of the rest of US healthcare. In addition to altering the course on quality and satisfaction, the VHA made a number of inroads in recent decades to contain costs. The improvements in cost containment, quality and satisfaction are attributed to the VHA's efforts over the last 25 years in three areas:

- 1) **Decentralization** of the VHA system from four United States regions into more than 100 independent medical centers with 21 Veterans Integrated Service Networks (VISNs), each able to budget and plan care for their geographical region. This decentralization included budgeting at the network-level. VISNs are given a fixed amount per enrolled veteran (capitation) for “basic care” patients and an additional fixed sum for “complex care patients”.
- 2) Focus on **measurement and reporting of performance** to improve quality. VISN managers are held accountable for the performance of their regional facilities in regard to providing preventive care and managing chronic conditions. Medical providers are given incentives to improve quality, access and patient satisfaction. For physicians, these incentives are financial bonuses linked to their performance.
- 3) Use of **health IT systems**. Pivotal for change was the entering of a new director, his focus on information management and the deployment of a nationally mandated EHR system called VistA.<sup>118</sup>

In the following we shall look closer at the development of VistA, and current developments in the VHA eHealth system.

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<sup>118</sup> For a case study on this organizational-technological transformation process, please visit: <https://www.isaca.org/Knowledge-Center/cobit/Documents/WaltersVARReport-June09.pdf>

## 13.2 VistA

VHA has developed and implemented a comprehensive health information system known as VistA, which has been built from the ground up with a clinical focus. The core of VistA was developed following an open source collaborative development model. The VHA approach has been to train clinicians to become programmers, rather than to train programmers to think like clinicians. Thus, many software developers in the VHA came from the ranks of its clinicians. Various parts of the system have been implemented also by other organizations within the public healthcare system as well as in other countries.<sup>119</sup>

Over 60 % of all physicians trained in the U.S. rotate through the VHA on clinical electives, making VistA the most familiar and widely used EHR in the U.S. Nearly half of all U.S. hospitals that have a complete (inpatient/outpatient) enterprise-wide implementation of an EHR are VA hospitals using VistA.

### *Timeline*<sup>120</sup>

In the late 1970's, the Office of Data Management and Telecommunications (ODM&T) was given the job to digitize the VHA nationwide. While the centralized computerization efforts were being implemented in batch transactions-based systems, local facilities acquired computers in a way higher rate than ODM&T initiatives. Local management was interested in conducting research and finding ways to improve care and efficiency through ICT and did not want to wait for the lengthy centralized developments to be implemented. The Department of Medicine & Surgery involved clinical experts and created the Computer-Assisted System Staff (CASS) Office. Local applications were developed by language programmers using the Massachusetts General Hospital Utility Multi-Programming System (MUMPS). The resulting Decentralized Hospital Computer Program included applications for administration, mental health, radiology and dietetics. VHA medical center and CASS Office personal also focused on re-usability and the adherence to an active data dictionary.

The ODM&T tried to shut down development, but DHCP developers continued their work. DHCP developers referred to themselves as the [HardHats](#), a virtual community of professionals interested and active in the deployment of both VA VISTA and Open VistA to this day. One of the reasons for the success of DHCP was that its robust infrastructure enabled individuals to develop independent applications. This allowed developers to work on DHCP applications separately while they waited for approval to put their modules together into a cohesive system. Eventually, in 1982, the VA Administration approved a policy giving facility directors the power to choose computer applications.<sup>121</sup>

**1985:** Computers at all VA Medical Centers are up and running. The Decentralized Hospital Computer Program information system (DHCP) is introduced, including clinical and administrative capabilities.

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<sup>119</sup> (DoD, National Cancer Institute), private organizations in the US (ex. Midland Memorial Hospital) (ex. Finland, Egypt, Mexico).

<sup>120</sup> Key sources are: <http://worldvista.sourceforge.net/vista/history/> and [http://www.ehealth.va.gov/docs/VistA\\_Monograph.pdf](http://www.ehealth.va.gov/docs/VistA_Monograph.pdf)

<sup>121</sup> For more information about the history of VistA see: [The History of the Hardhats](#)

**1995:** The Veterans Health Information Systems and Technology Architecture (VistA) is introduced. VistA supports both ambulatory and inpatient care, and includes several significant enhancements to the original DHCP system. It connects VHA facilities' workstations and PCs with nationally mandated and locally adapted software applications that are accessed by end users through a graphical user interface known as the Computerized Patient Record System (CPRS).

**1999:** VistA Imaging launched, integrating clinical images, scanned documents, and other non-textual data into the patient's electronic medical record. Captured images are combined with text data to facilitate a clinician's task of correlating information and making timely and accurate patient care decisions.

**2001:** VistA is the largest system in use in the US, with medical documentation and ordering available at every VA hospital in the country.

**2002:** 90.6 % of all inpatient and outpatient pharmacy orders were entered by the provider.

**2005:** VHA launches ambitious and controversial plans for an organizational and ICT overhaul and consolidation process. The department laid out ambitious plans to consolidate control over what had become a sprawling, aging and unwieldy system of computer and communications technologies spread across the department's more than 1,000 medical centers, clinics, nursing homes and veterans' centers. All IT budgeting, planning and development was centralized under the control of VA's Office of Information and Technology, while placing a premium on encrypting, securing and accounting for every piece of computer hardware in the system.

**2006:** IT security breach compromised the confidential information of some 26 million veterans, prompting the already introduced plan for centralized control and consolidation of health IT in VHA.

**2007:** A set of protocols is developed and used by the VHA to transfer data between hospitals and clinics within the pilot project. This is the first effort to view a single patient record so that VistA becomes truly interoperable among the 128 sites running VistA today.

**2009:** President Barack Obama charged VA and DoD to work together to define and build a seamless system of integration so that when a member of the Armed Forces separates from the military, he or she will no longer have to walk paperwork from a DoD duty station to a local VA health center. Their electronic records will transition along with them and remain with them forever.

**2011:** The US Government invests 5 billion dollar in development of VistA4. The development is to be based on open source. VHA launches [OSEHRA](#), the central governing body of a new open source software community which will be the core developers of all future development of VistA. In addition the VA needs to bring the external VistA community and private sector into the fold.<sup>122</sup>

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<sup>122</sup> This has all kinds of ramifications, from how to manage vendors to how to get the internal development teams in the VA to work with OSEHRA (the VA has over 1,300 developers and between 5,000 to 10,000 physicians and nurses who volunteer their time to enhance VistA).

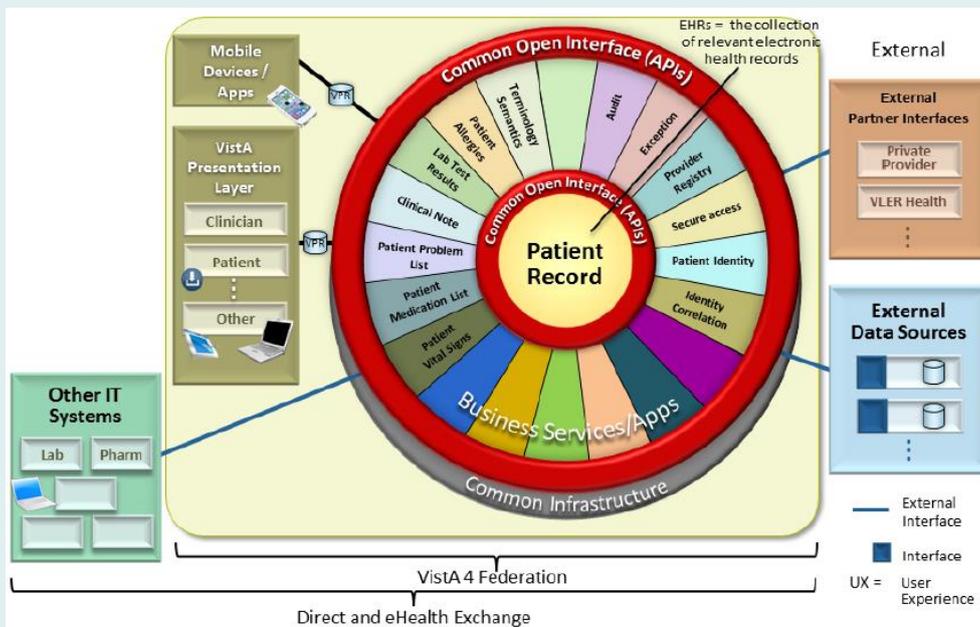
**2014:** [VISTA Evolution Program](#) and [The Vista 4 Product Roadmap](#) is launched to develop Vista 4, the next evolution of Vista into a generation 3 EHR within 2018. Vista4 will harness the core of software and business processes embedded within Vista and apply a modern computing architecture that is modular and extensible.

### 13.2.1 The Vista Evolution Program and Vista4

Underlying the Vista Evolution program and the development of Vista4 is the shift in care delivery to patient-centric team-based care which requires a shift from an EHR that is encounter based and operates in many respects like a digitized version of a paper patient chart to an EHR that is care-plan based and facilitates collaboration and data exchange among a distributed care team. The objective is thus an EHR that provides a new integrated user experience for all members of the healthcare team, including the patient, with underlying care coordination, decision support, and ancillary services interoperating seamlessly with multiple sources of data.

The Vista Evolution Program aims to enable both seamless interoperability with DoD and other healthcare providers, while modernizing key Vista architecture and capabilities. Embracing open standards and adhering to a “cloud first” infrastructure policy, which involves data center consolidation and a move to virtualization of both back-end and front-end systems, the aim is for an efficient solution enabling data sharing and fostering a collaborative approach to future growth. The product roadmap incorporates significant functional enhancements and improved integration to clinical ancillary systems (laboratory, pharmacy and radiology) and the adoption of clinical coding standards that will improve interoperability among care settings and support evidence based clinical decision support (CDS). This roadmap will also lay the groundwork for improved Medical Device Integration (MDI) as these industry standards mature.

Figure 41. Layered Vista 4 SOA Design



Source: VHA

### 13.2.2 Infrastructure

The program aims to develop an interoperable, secure and reliable technical infrastructure while adopting enhancements outlined by the VA Enterprise Infrastructure design inclusive of regional Data Centers and a fault-tolerant NextGen Wide Area Network (WAN).

VistA's applications share a common infrastructure that integrates them at the database level. Though the enterprise solution allows flexible local control over content and configuration, a set of common data dictionary, database standards, programming conventions and technical reviews avoid incompatibility between the different applications. When a problem of different site-specific data dictionary appears, a national standard dictionary is used as Interlingua to fix the problem.

A set of core design principles guide the development carried out under the VistA Evolution Program, ensuring that interoperability, clinical and IT objectives are met with consistency and efficiency:

- Service Oriented Architecture (SOA). Software applications will use common enterprise services to facilitate re-use, achieve economies of scale, and to reduce development and maintenance costs. Both application services and infrastructure services (such as messaging or Enterprise Service Bus (ESB) software) will adhere to SOA principles.
- Open Architecture. Open standards are a key enabler of interoperability and the sharing of computable health data between VA, DoD and other healthcare partners. In addition to data standards, VA will also document and make widely available application program interfaces (APIs) and technical specifications for both VistA legacy and new or enhanced code. Collaboration with innovators will continue through OSEHRA and other outreach efforts, where Government-developed and third party open source code will be shared.
- Agile Development. Agile development methods will be used to create an environment that is responsive to the needs of end users. An integrated team of program managers, engineers, designers, and end users will take strategic priorities from both clinical and IT leadership, and execute decisions at the lowest level of granularity appropriate for the task.
- Robust IT Infrastructure. To provide flexible, reliable, and cost-effective support for production operations and future innovation, IT infrastructure will comply with data center consolidation, virtualization, and "cloud first" guidelines.

### 13.2.3 Infostructure

VistA4 adopts Consolidated Clinical Document Architecture (CCDA) for external exchanges, thus following National standards, and adopting HL7's Fast Healthcare Interoperability Resources (FHIR) standard for real-time, dynamic DoD/VA exchanges.

The use of common terminology based on National Standards, enables all parties to understand the meaning of common terms. If national standards do not exist as of the date on which the record is being established, the default process would be to leverage the Health Data Dictionary until such national standards are established.

The DoD/VA Interoperability approach use harmonized physical models for data in motion, based on Extensible Markup Language (XML) and JSON (Java Script Object Notation).

The VistA 4 Product Roadmap leverages open standards endorsed by the Office of the National Coordinator and adheres to key open architecture tenets such as open transport formats (e.g., HL7

messaging), open interface specifications, and design patterns that enable an open and scalable solution.

VA and DoD have committed to achieving Meaningful Use (MU), as defined by the American Recovery and Reinvestment Act. To meet this commitment, VA and DoD is implementing the EHR enhancements required for MU certification. VA/DoD interoperability will evolve over time to allow VA and DoD clinicians to use the same medical coding systems more natively, facilitating more precise communication, and reducing the dependence on translation.

#### **13.2.4 Privacy, Information Security, Access Control**

There are approximately 140 databases in use across the country in VA facilities that are accessible via VistA systems. Because of this wide distribution of information, there is great risk that individual patient data is kept under more than one identification number. The [master patient index \(MPI\)](#) has been created to support maintenance of a unique patient identifier and a single master index of all VA patients, and to allow messaging of patient information among systems.

The implementation of VistA 4 will meet or exceed all Federal information security requirements and will utilize approved [VA Office of Information Technology ProPath System Development Lifecycle \(SDLC\) process](#) and the [VA Office of Information Security's Software Assurance \(SwA\) Program](#). These will improve both patient identity security and information system security.

Additional security will be achieved through VA's Information Security Continuous Monitoring (ISCM) and Information Security Risk Management (ISRM) programs to manage information system risk.

VistA 4 will enhance patient data security by using improved Technical Controls, which will include SwA, ISCM, ISRM, and data encryption, both in transit and at rest.

#### **13.2.5 Shared eHealth Components and Services**

VistA is an enterprise-wide information system built around an Electronic Health Record. It consists of nearly 160 integrated software modules for clinical care, financial functions, and infrastructure. VistA does not include a billing system, since healthcare is free of charge for patients who qualify for the VA program. A complete description and list of all applications can be found at the [Vista website](#) or in [the VistA Monograph](#). In the following, we list some of the main features, as well as further developments to occur from the VistA Evolution program.

The [Computerized Patient Record System \(CPRS\)](#) provides a client-server interface that allows healthcare providers to review and update a patient's electronic medical record. CPRS provides consistent, event-driven, Windows-style interface to healthcare workers at different sites. CPRS capabilities include:

- A Real-Time Order Checking System that alerts clinicians during the ordering session that a possible problem could exist if the order is processed
- A Notification System that immediately alerts clinicians about clinically significant events
- A Patient Posting System, displayed on every CPRS screen that alerts clinicians to issues related specifically to the patient, including crisis notes, warning, adverse reactions, and advance directives
- A Clinical Reminder System that allows caregivers to track and improve preventive healthcare for patients and ensure timely clinical interventions are initiated.

- Remote Data View functionality that allows clinicians to view a patient's medical history from other VA facilities to ensure the clinician has access to all clinically relevant data available at VA facilities.
- Ability to place orders, including medications, special procedures, x-rays, patient care nursing orders, diets, and laboratory tests.

[Barcode Medication Administration](#) provides a real-time, point-of-care solution for validating the administration of unit dose and Intravenous medications to inpatients in medical centers. The solution improves the accuracy of the medication administration process, and increase the efficiency of the administration documentation process. As a clinician scans each patient wristband and medication using a bar code scanner, the system validates the patient and the medication, and that the medication is ordered, timely, and in the correct dosage. At the same time, BCMA electronically updates the patient's medication history. The software is fully compatible with other VistA applications

[VistA Imaging System](#) integrates clinical images, scanned documents, and other non-textual data into the patient's electronic medical record. The VistA Imaging TeleReader allows images acquired at one facility to be read by specialists at other, centralized locations, enabling real-time consultations between personnel in different locations on the basis of shared viewing.

**Joint Legacy Viewer (JLV)** is the EHR viewer available to users in both DoD and VA, providing three major advantages over older viewers. JLV combines data from the same clinical domain into one table, arranging it in chronological order, allowing clinicians to scan results and identify trends. JLV allows the user to configure displays to support various workflows (e.g., clinicians can create and save a view with tables of labs and medications, side-by-side, to evaluate the effectiveness of medications). JLV can display certain data, such as lab tests or medications, mapped to standard national codes in seven clinical domains, enable comparison of data between systems, understand trends, and develop a more complete picture of a patient's history.

**Health Management Platform (HMP)** delivery of new GUI tools to support Google-like search across an entire patient record, InfoButtons that provide context-specific knowledge resources for medications and patient education, improved medication reviews for enhanced safety, tasks for team-based coordination and follow-up, and newsfeed for rapid, chronological review of a patient's care and results.

**Clinical Decision Support** includes alerts and reminders to care providers and Veterans, Service members, and their dependents. CDS includes clinical guidelines, condition-specific order sets, focused patient data reports and summaries, documentation templates, diagnostic support, and contextually relevant reference information among other tools. Functions are displayed in the GUI.

### 13.2.6 Digital Services for Citizens

Through the two, interrelated initiatives *My HealtheVet* and *Blue button*, the VA grants easier access to patient information and self-entered information in order to enable patients to be better partners with their health teams and make informed decisions about their health.

[MyHealtheVet](#) is a web-based personal health record (PHR) designed for patients and their families to help them understand and manage their health. It is also a communication tool to be used for

non-urgent health related issues. Users can search an online library of trusted consumer health information, as well as, create and access their own personal health records. The web site also provides information about VA benefits, services, news and events.

By registering a secure User ID and Password members can:

- Create and manage your own personal Health Journal of allergies & immunizations, insurance information, self-entered logs of blood pressure, blood sugar, weight, cholesterol levels and other data
- Record their military health history
- Order their VA prescriptions online
- Print out information from their self-entered records to share with VA or non-VA providers
- View future appointments
- View lab reports
- Secure message your Primary Care Provider and Team

[VA Blue Button](#) enables veterans to generate and download an electronic file that contains their available health information from *My HealthVet*. VA Open Notes “opens” clinical notes, allowing patients to read their healthcare team’s notes from appointments and hospital stays. The aim is to provide patients with the ability to read and discuss notes with their healthcare teams, family and Caregivers allowing them to gain better control over their healthcare.

[VA Continuity of Care Document \(VA CCD\)](#) is a summary of your key health information that can be shared between healthcare providers to support coordination of care. This information can be viewed by health computer systems and providers outside VA (via an *.XML* file), or be uploaded into other applications. A PDF file is also available.

### **13.2.7 Secondary Use of Data**

Vista provides a large repository of information in a consistent file format. This enables VHA to conduct extensive [patient data analysis](#). For example, a look at data from three VA clinics has helped physicians adjust hypertension treatment to account for seasonal fluctuations in blood pressure and for differing factors such as location, weight, age and gender.

The recently launched [Million Veteran Program](#) aims to collect (and de-identify) PHI from volunteer veterans as a means of studying how genetics affect overall health.

## 14 Canada

### 14.1 Demographic Data and Political Tradition

Population (2013)	35 158 304
Area (km <sup>2</sup> )	9 984 670
Political tradition	Federal parliamentary constitutional monarchy
Administrative levels	State, province + territory

### 14.2 Key Figures for Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	81.1
<b>Expenditure on health</b>	
In percent of GDP	11.2
Per capita (USD purchasing power parity)	4 522
Public financing (% of total expenditure)	69.9
Private financing (% of total expenditure)	30.1
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	2.4
Practicing nurses (per 1000 population)	9.3
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	7.4 (2010)
Hospital discharges (per 1000 population)	82
Total hospital beds (per 1000 population)	2,74
Average length of stay, all causes (days)	7,4
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	100
Out-of-pocket medical spending (% of household consumption)	2.4

Source: OECD 2013

### 14.3 Gathering Information on the Canadian Case

The empirical material for this chapter is gathered through

Desktop research, May-June 2013 and October 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Canadian healthcare system, eHealth strategy, key actors and initiatives.

### 14.4 Financing, Governing and Organizing Healthcare

Canada is a federation with two constitutionally recognized orders of government. The first order is the central or “federal” government. The second, but constitutionally equal order of government consists of the 10 provincial governments, which bear the responsibility for a broad range of social policy programs and services including the bulk of publically financed and administered health services. In addition, although they do not enjoy the constitutional status of the provinces, the three

northern territories exercise many of the same policy and program responsibilities, including those for healthcare.

Canada has a highly decentralized health system with a mixed model of public and private health delivery. Healthcare is publically funded often referred to as "medicare", while the delivery of the majority of primary health services is private and thus decentralized.

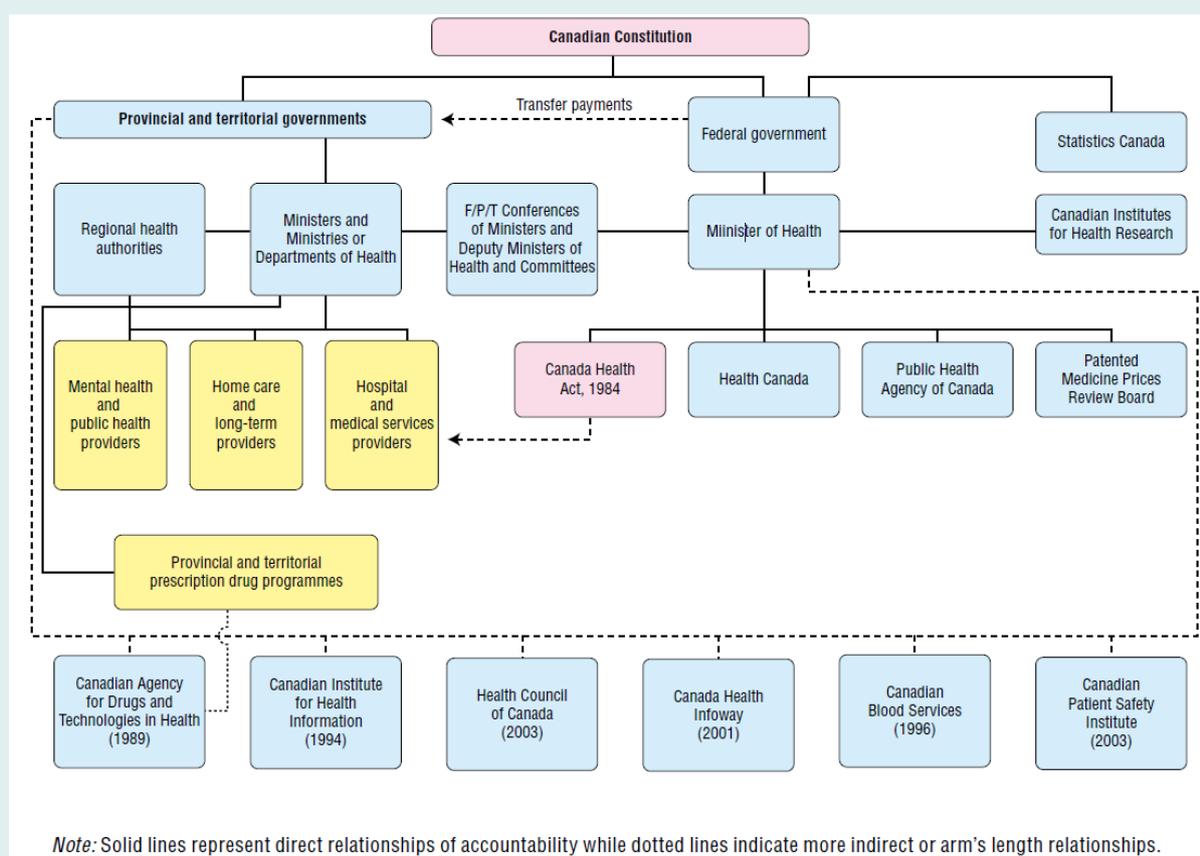
Medicare is designed to ensure that all residents have reasonable access to medically necessary hospital and physician services, on a prepaid basis. Healthcare is mostly free at the point of use, financed by income taxes. Private health expenditure accounts for 30 % which accounts for medication, prescription glasses or dental care, which is paid out-of-pocket or private insurance.



Federal government, through [the Department of Health](#), assures basic standards for hospital, diagnostic and medical care services guided by the provisions of the Canada Health Act of 1984. The federal government's activities range from funding and facilitating data gathering and research to regulating prescription drugs and public health while continuing to support the national dimensions of medicare through large funding transfers to the provinces and territories.

The jurisdictions are responsible for the management, organization and delivery of health services for their residents. Geographically organized Regional Health Authorities (RHAs) operate at an intermediate level between jurisdictions health ministries and individual providers, and have a legal mandate to plan the coordination and continuity of care among a host of healthcare organizations and providers within a defined geographical area either by delivering the services directly or by contracting with other healthcare organizations and providers. Delivery is effected through private profit-making, private non-profit-making and public organizations as well as by physicians who receive remuneration from provincial ministries of health.

Figure 42. The Canadian Healthcare System



Source: WHO, *HiT Series*

Due to the decentralized nature of health delivery, patient pathways vary considerably. Typically, a patient pathway starts with a visit to a GP who provides primary medical services on a fee-for-service basis and act as a gatekeeper to specialist care. While patients are free to change their family physicians, most choose to have long-standing relationships with one physician. In cases where the patient does not have a regular family physician or needs help after regular clinic hours, the first point of contact may be a walk-in medical clinic or a hospital emergency department. The vast majority of GPs is profit-making professional contractors, and is not directly employed by either the RHAs or jurisdictions.

Virtually all secondary, tertiary and emergency care, as well as the majority of specialized ambulatory care, is performed in public or non-profit-making hospitals although some specialized ambulatory and advanced diagnostic services may be provided in private, profit-making clinics. Hospitals are both owned by RHAs, and are private, largely non-profit-making, corporations. Specialists who provide acute services are private, independent contractors. Most services supporting primary and acute care, including ambulance, blood and laboratory services as well as the ancillary hospital services, are private.

Illness prevention services including disease screening may be provided by a GP, a public health office or a dedicated screening program.

Rehabilitation and long-term care policies and services, including home and community care vary considerably among provinces and territories. Long-term care facilities are divided between public and private (profit-making and non-profit-making). The majority of dental care, vision care, psychology and rehabilitation services are privately funded and delivered by independent professionals.

### ***Healthcare reform***

There have been no major pan-Canadian health reform initiatives since 2005. Jurisdictions, however, have concentrated on two categories of reform, one involving the reorganization or fine tuning of their regional health systems, and the second linked to improving the quality and timeliness of – and patient experience with – primary, acute and chronic care.

As a consequence of the constitutional division of powers and the decentralized nature of health administration and delivery, there is no single agency responsible for system-wide national planning. Instead, pan-Canadian initiatives are often the product of intergovernmental agreements, committees and agencies that do a limited amount of high-level strategic planning, most often on a sector-by-sector basis such as HTA, administrative data collection and dissemination, and of particular interest in our case, EHRs.

The responsibility for ICT systems in healthcare lies with the jurisdictions, who have invested in health ICT infrastructures. Reflecting the federal political tradition, a plurality of information systems are in place for the collection, reporting and analysis of health data. Several success stories exist.

- At the provincial level, [British Columbia's PharmaNet system](#) has since 1995 connected all the pharmacies in the province to a centralized medication profile database. As a result, any pharmacy and hospital emergency department in the province has 24/7 access to all the medications any patient has received in the previous fourteen months.
- At a regional level, the Capital Health Authority based in Edmonton, Alberta had islands of patient information until 2004. After only eleven months in development, [Capital Health launched netCARE](#), Canada's first region-wide integrated EHR. For the first time, authorized clinicians had immediate computer access to up-to-date patient records across systems. With the success of the netCARE portal, the Alberta Government has selected it as the platform for a province-wide EHR.
- At a hospital level, the University Health Network, a large teaching hospital on three sites in Toronto has successfully implemented [CPOE \(computerized physician order entry\)](#) including over 50,000 medication orders a month. As a result, UHN has been able to demonstrate a reduction in medication errors and adverse drug events.

Notwithstanding these achievements, the national aim of providing all Canadians with a shared national EHR system within 2016 is not likely to be achieved. In 2015 EMR coverage among GPs is 77 %. Canada continues to lag behind other Western countries in adopting EMRs.<sup>123</sup>

### ***14.5 eHealth in Canada: Past, Present and Future***

In 2001 the federal government established [Canada Health Infoway](#) to accelerate the eHealth agenda and to create a national system of interoperable electronic health records. Canada Health Infoway is an independent, not-for-profit organization founded by the federal government. The deputy Ministers of health for the 10 provinces, three territories and the federal government make up the Members of the Corporation. Some of these members also serve on Infoway's Board of Directors, which includes leaders from Canada's public, health, legal, financial, and technology sectors.

Infoway invests in a common, pan-Canadian framework of electronic health record systems where best practices and successful projects in one region can be shared or replicated in another. As a strategic investor, Infoway works in collaboration with health ministries, regional authorities, other healthcare organizations and information system vendors to best align Infoway's investments with jurisdictional plans and to leverage existing solutions. Once investment decisions are made, public sector partners lead the development and implementation of EHR solutions. Since 2001, Infoway has been allocated C\$2.1 billion (1 C\$ = 6, 50 NOK) in federal government funding.

Infoway also participates in project planning and monitors the implementation of projects by the provinces and territories as well as the quality of deliverables.

The concept for the Canadian national EHR entails building the infrastructure and then let the jurisdictions implement applications that use this infrastructure. A fully functional electronic health record (EHR) will allow authorized healthcare professionals to view and update a patient's health record, anywhere and anytime.

The CHI financial investments have had a strong steering effect on the agenda in Canada. Most provinces did not have and most continue not to have the fiscal strength to make large scale investments in their HIT infrastructure. CHI funding filled this fiscal gap and drove development of core health IT infrastructure such as registries, repositories and health information exchange hubs as well as, more, recently targeted support for EMR programs in all jurisdictions.

#### ***Timeline***

**1999:** All the jurisdictions agree to a broad strategy to build an Information highway for the healthcare system. The Federal government commits an initial \$500 million to support this plan and establishes Canada Health Infoway to accelerate the eHealth agenda and create an interoperable pan-Canadian electronic health record.

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<http://content.healthaffairs.org/content/31/12/2805.full?keytype=ref&siteid=healthaff&ijkey=Wx1r2YCSnJVL>.

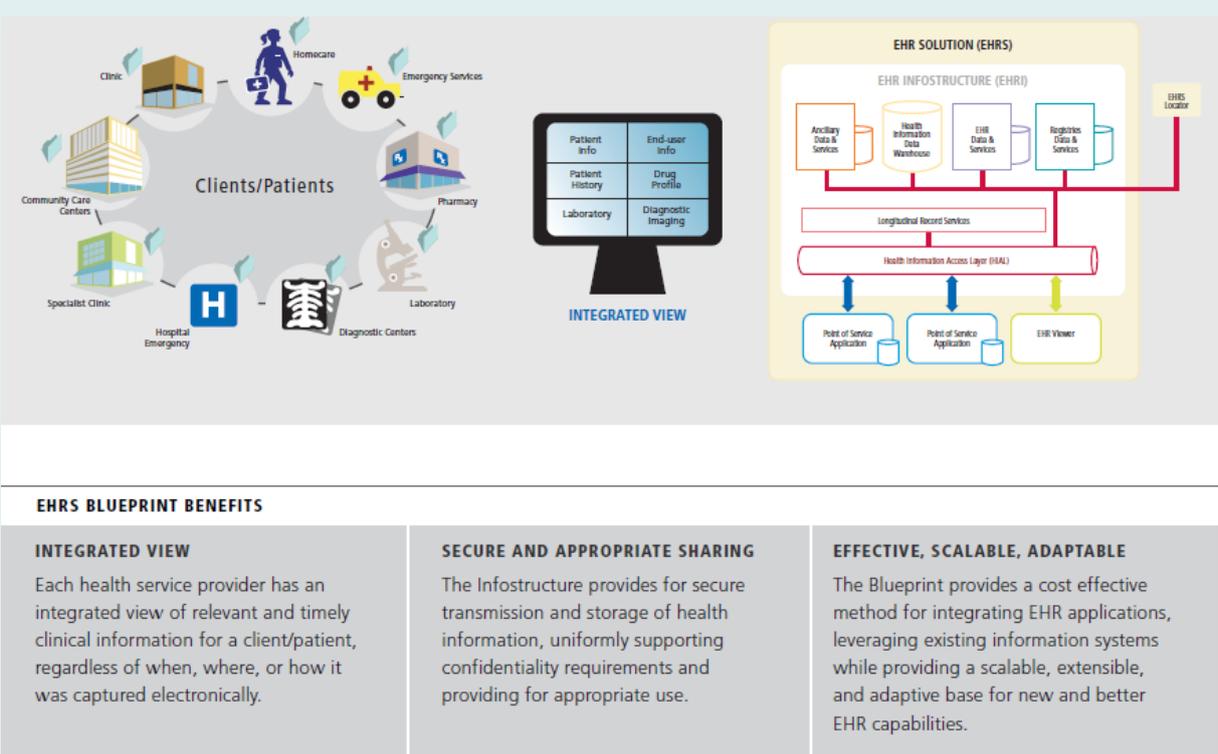
**2003:** Recognizing that each jurisdiction will have an EHR system adapted to its needs, in order to facilitate national interoperability between systems, Infoway published the Electronic Health Record Solution Blueprint. The Blueprint provides a comprehensive description of the components necessary for the interoperable EHR and describes, in broad terms, how the components are envisioned to work together. The Blueprint is essentially a conceptual architecture for the interoperable EHR.

**2006:** Infoway releases a revised blueprint, which now includes more detail on how standards support the sharing of health information. It also includes more on how they comply with federal, provincial, and territorial requirements as well as privacy and security requirements across jurisdictions.

**14.6 Current Canadian eHealth System**

The provinces and territories are responsible for developing their own EHR strategies and for proposing projects to Infoway that align with the Blueprint, the standards, and the eligibility criteria. They are responsible for implementing the projects, and for the cost of operating and maintaining EHR systems. Because the total amount of funding that Infoway will provide for a project is capped when the project is approved, the provinces and territories assume all the risk of cost overruns.

**Figure 43. The Canadian National EHR solution**



EHRIS BLUEPRINT BENEFITS		
<p><b>INTEGRATED VIEW</b></p> <p>Each health service provider has an integrated view of relevant and timely clinical information for a client/patient, regardless of when, where, or how it was captured electronically.</p>	<p><b>SECURE AND APPROPRIATE SHARING</b></p> <p>The Infostructure provides for secure transmission and storage of health information, uniformly supporting confidentiality requirements and providing for appropriate use.</p>	<p><b>EFFECTIVE, SCALABLE, ADAPTABLE</b></p> <p>The Blueprint provides a cost effective method for integrating EHR applications, leveraging existing information systems while providing a scalable, extensible, and adaptive base for new and better EHR capabilities.</p>

Source: Infoway

Infoway, as a national mechanism for an interoperable eHealth system, works on two levels. On the one hand, it develops the national infrastructure for sharing health information. On the other hand, it funds eHealth projects in the jurisdictions that comply with national infrastructure and standards.

As a strategic investor, Infoway identify priorities, along with measurable goals and targets, and provide a roadmap for the development of the various component systems of an EHR. Infoway funds

projects using a gated funding model that ties reimbursement to the achievement of project milestones. More information on the Infoway Portfolio office is available [here](#).

[The Electronic Health Record Solutions Blueprint](#) provides an information systems architecture that can be used consistently by Infoway sponsored projects to incrementally and progressively implement interoperable EHR Solutions. This architecture expresses the current and anticipated requirements for the sharing of EHR information in the healthcare enterprise across Canada. It provides a set of design patterns for building the supporting EHR Infostructure and for interfacing the many applications at the point of service to that infostructure.

#### 14.6.1 Infrastructure

[The Blueprint is an enterprise systems architecture](#) that uses principles of a Services Oriented Architecture to enable the applications at the many points of service to use one standards-based set of interfaces to exchange information through a shared EHR Infostructure. There is a messaging-oriented model for communication between the local EHR systems. The Blueprint describes how each point of service application can connect to the shared infrastructure using a common set of interface standards, rather than connecting to each other directly. These interfaces are handled by the Health Information Access Layer which provides common services to support, for example, authorization and authentication of users and logging and auditing of all accesses. Point of service applications send distinct information about clients/patients to a set of shared information repositories that are managed by the Longitudinal Record Services. The applications (or an integrated viewer) can then request EHR information from the Infostructure using the same mechanisms, accessing relevant EHR information captured by different health disciplines, in different care settings, and potentially in many jurisdictions across Canada. Each infrastructure can communicate with other infrastructures, collaborating to deliver clinically relevant information where and when it is needed, regardless of where it was originally captured.

**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
- 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.

**Health information access layer** works as a portal that allows information in different languages and forms to be shared. It provides a standardized method for PoS applications to be interconnected with EHR, 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 EHR 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.

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. The EHR storage then receives that information and stores it in its local database until the data is needed by another authorized user.

#### 14.6.2 Infostructure

The EHR consists of software solutions for the EHR, data definitions for the EHR and messaging standards for the EHR.

*Infoway* has established [pan-Canadian standards](#) that enable the electronic sharing of healthcare information between best of breed healthcare solutions. These standards lead to improved patient safety and better outcomes for consumers, clinicians and the healthcare system.

A pan-Canadian Standard is a document created and approved by consensus among stakeholders. The pan-Canadian standards are based on [International Standards](#) (HL7 v3, snomed CT, CeRx Pharmacy Messages, LOINC Terminology). See the [pan-Canadian standards here](#).

#### 14.6.3 Privacy, Information Security, Access Control

Jurisdictions are responsible for ensuring that the implemented EHR systems comply with their own privacy laws, and for helping doctors, nurses, pharmacists, and other healthcare professionals understand and use EHRs.

For the national EHR, [Infoway's EHR Privacy and Security conceptual Architecture](#) helps ensure that future interoperable EHR systems will comply with federal/provincial/territorial, as well as cross-jurisdictional Privacy and Security (P&S) requirements.

The PSCA sets out ten components that are critical to the privacy and security of personal health information in an interoperable electronic health record environment. These services include:

1. User identity management services – activities related to accurately identifying users of the system, such as registering users, assigning roles that define access privileges, and managing changes in their status.
2. User authentication services – those activities needed to establish the validity of the claimed identity of a user logging into the system.
3. Access control services – models that can be used to control access to data based on either the individual's specific role in the healthcare system, their association with a group or discretionary access, whereby an individual, such as a physician, has authority to grant access to the record.
4. Informational consent directives management services - activities related to recording, managing, applying, logging and overriding an individuals' consent directives.
5. Identity protection services - the real time de-identification and re-identification of personal information during storage and use of PHI.

6. Anonymization services – activities related to removing all personal identifiers from a record to enable use of the data for secondary analysis and research purposes.
7. Encryption services – activities related to creating, renewing and revoking encryption keys and the application of cryptography during the encryption of PHI within databases, in stored (archived) files, during PHI transmission and processes used during authentication of systems and system users.
8. Digital signature services – activities related to the secure use of electronic signatures.
9. Secure audit services – activities involved in secure logging of access to and use of the system.
10. General security services – that address activities related to scanning for viruses, secure back-up, archiving data, destroying data, and restoration of data.

#### 14.6.4 Shared eHealth Components and Services

[Patient/Client registry and Provider registry](#) - identify patients and authorized clinicians. Virtually all Canadians and practicing physicians have been uniquely identified in the registries that are established in each province and territory.

[Drug information system](#) enables authorized users to access, manage, share and safeguard patients' medication histories.

[Laboratory information system](#) allows laboratory technicians to enter results into a database that will be linked to the patient's EHR and made available for viewing. Laboratory test results are increasingly being linked to individuals' electronic health records.

[Diagnostic Imaging Systems](#) enable authorized healthcare providers to access and view diagnostic images and associated reports regardless of where they were created. DI systems electronically collect, store, manage, distribute and display patient radiology images and reports entirely in digital format, without the need for film. Virtually all diagnostic images taken at publicly-funded facilities in Canada are digital, stored in a repository and available for access by authorized clinicians.

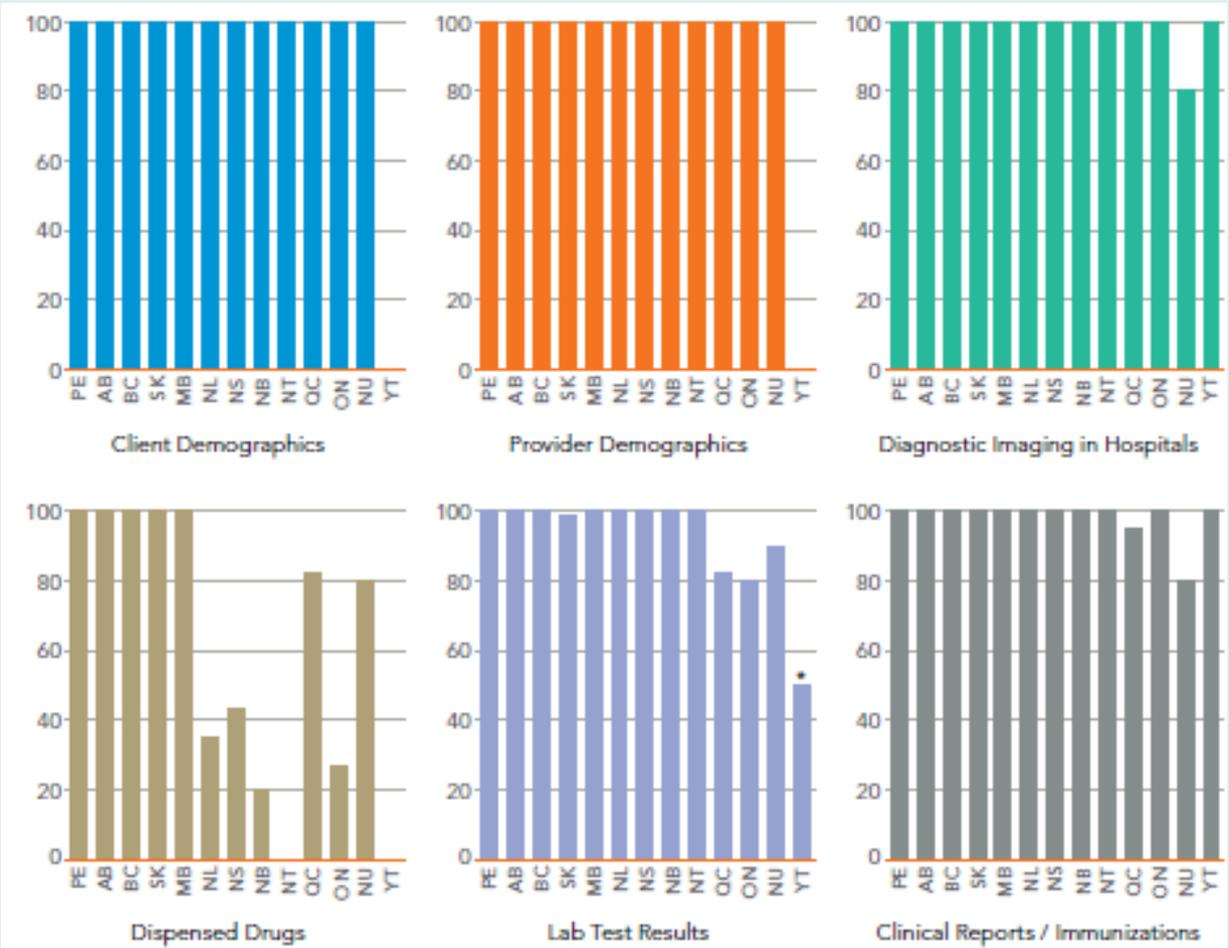
[Change management model](#) and belonging tools are used to guide the implementation of eHealth initiatives at a national level. It is recognized that successful implementation of digital health solutions occurs when a technology is effectively embedded into daily workflows and results in widespread adoption and other long-term benefits including improved patient care and productivity gains. Change management supports people as technology is implemented and includes a wide range of activities including workflow adaptation, behavioural and cultural transformation.

[National Interoperable EHR](#) is the end goal of the Canadian Infoway collaboration. It should provide each individual Canadian with a secure and private record of their health history and care within the health system. The record is available to authorized health providers and the individual anywhere, anytime. This record is designed to facilitate the sharing of data across the continuum of care, across healthcare delivery organizations and across geographical areas. [A concept of what an authorized clinician may be able to view from an iEHR.](#)

Infoway and the jurisdictions began the national EHR initiative by focusing on building six core systems to collect information electronically: client and provider demographics, diagnostic images,

profiles of dispensed drugs, laboratory test results and clinical reports or immunizations. This information constitutes the essence of an EHR. Infoway tracks each jurisdiction’s progress on availability of data in each of the six core systems individually (see figure 43).

Figure 44. Availability of EHR information by Jurisdiction



Source: Infoway

14.6.5 EHR Landscape

While the Blueprint represents the pan-Canadian architecture for EHRs, for most jurisdictions, the EHR initiative is just one part of an overall eHealth strategy. Every jurisdiction will have its own EHR system that is customized to their needs and nature. Some larger jurisdictions will have a number of EHRs that work together in a region.

14.6.6 Digital Services for Citizens

Infoway has been investing in [digital services for citizens](#) such as eBooking, eVisits, Patient portals and eViews, Remote Patient Monitoring, eRequests for prescription renewals and refills.

14.6.7 Secondary Use of Data

Established in 1994, [the Canadian Institute for Health Information \(CIHI\)](#) was a response to the desire for a nationally coordinated approach to gathering and analyzing financial and administrative data from all levels of the healthcare system. Its core functions include identifying and defining national health indicators and frameworks, coordinating the development and maintenance of pan-Canadian

data standards, developing and managing health databases and registries, and disseminating health data through research reports. By 2011, CIHI was maintaining a total of 27 databases and clinical registries.

CIHI coordinates the collection and dissemination of health data, much of which is administrative data provided by the provinces and territories. CIHI works with F/P/T governments in establishing and maintaining data definitions and quality standards. The agency also works with provider organizations in maintaining databases, including physician and hospital discharge databases.

At the federal level, [Statistics Canada](#) is governed by a legislative framework – the Statistics Act – that makes the provision of basic census data compulsory while protecting individual privacy and confidentiality. Statistics Canada collects population health data through both the national census taken every five years and large-sample health surveys.

Since the 1990s, privacy has emerged as a major issue in health data collection and dissemination. Since jurisdiction over health information is shared among the different levels of governments, the result is a patchwork of health information and privacy laws in Canada. At the jurisdictional level, most jurisdictions have general laws in place to protect privacy and confidentiality, although some have specific legislation to protect health information. This latter development is, in part, a response to the public backlash to initial efforts to establish electronic health information networks and EHRs, including patient records. While privacy concerns about health records pre-dated such efforts, the potential use of EHRs has highlighted these concerns.

#### ***14.7 Final Reflections***

While a report from [The National Audit Office released in 2010](#) identified important achievements of Canada Health Infoway's e-health plan, including funding, national standards, patient registries and digital imaging, there was also the recognition that Canada lags behind other countries in the adoption of EHRs. Low rates of adoption were attributed to the lack of meaningful engagement of clinicians; poor alignment of the eHealth plan and implementation strategy with the clinical and business needs of clinicians and the healthcare system; lack of flexibility in incorporating change; and a focus on national rather than regional interoperability.

A key finding in the report is the absence of an eHealth policy to align the investment in information technology with the priorities of the healthcare system and of healthcare providers in order to accelerate adoption and achieve early return on the investment. Canada Health Infoway is to a large extent seen as a funding agency, not a policy-setting body. The lack of a national policy or harmonized provincial policy to guide investment and adoption was seen as a problem. Moreover, inadequate attention to clinicians, the key users of electronic health records, was viewed as a critical ingredient missing from the e-health vision.

A complete EHR requires the development or upgrading of a number of systems. When there is no EHR strategic plan at the provincial level or when links between plans are weak, it is unclear when component systems will be developed or upgraded; it is also unclear which systems will need to be upgraded. Furthermore, there is a risk that the projects undertaken will not be consistent with the goals and priorities of the overall EHR initiative and that the needs of the users will not be met.

The report points to the lack of a testing system for the jurisdictional EHR solutions. Without a conformance testing on EHR systems, Infoway cannot ensure that the Blueprint framework and standards have been correctly implemented. Consequently, Infoway does not have sufficient assurance that EHR systems will be compatible across the country. It appears that the focus for the provinces is to ensure compatibility within their jurisdictions. This approach is based on the fact that the majority of people seek healthcare within their home province. Provinces have reported that they intend to comply with standards, but it is too soon to have certainty about whether the systems in their jurisdictions will be compatible. In addition, it is not clear when existing systems will be upgraded, if necessary, to meet standards for compatibility.

The report argues that stronger leadership is needed to implement national standards to address the challenges of migrating away from existing legacy systems. Moreover, the Canada Health Infoway Blueprint needed to be less top-down, and more flexible and adaptive to accommodate changes in technology and feedback from implementation experiences. Although national and even international standards might be highly desirable national interoperability might not be a priority in the jurisdictions and enterprises among whom strong voices instead suggested that efforts be devoted to achieving effective regional interoperability both to support clinical adoption and to increase the speed of implementing systems to support the continuum of care. The point being that that Infoway was unreasonably ambitious in its attempts to attain national interoperability when stakeholders considered regional interoperability to be more important, less expensive and easier to implement. Indeed, it was pointed out, most healthcare is rarely delivered outside provincial jurisdictions, which manage the healthcare system.

In a study based on interviews with policy and opinion leaders from different stakeholder groups Rozenblum *et al.* found that Canada's eHealth plan has not yet addressed issues around key components needed for clinicians to actually use electronic health records in the delivery of care.<sup>124</sup> Indeed, key components such as problem lists, clinical notes and computerized decision-support were not in the eHealth investment plan. An overly "top-down" approach and insufficient engagement of clinicians were aspects considered by our participants, as well as by other Canadian critics, to have contributed to low adoption rates. Although a "top-down, technical, architecture-first" approach may eventually lead to the same outcome as a "bottom-up, clinical needs first" approach would, the top-down approach was considered to be too slow, expensive and inefficient by some of the participants.

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<sup>124</sup> <http://www.cmaj.ca/content/early/2011/02/22/cmaj.100856.1.full.pdf>

## 15 Australia

### 15.1 Demographic Data and Political Tradition

Population (2013)	23 130 900
Area (km <sup>2</sup> )	7 692 024
Political tradition	Federal parliamentary constitutional monarchy
Administrative levels	State (Commonwealth), state (and territory)

### 15.2 Key Figures for Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	81.9
<b>Expenditure on health</b>	
In percent of GDP	8.9 (2010)
Per capita (USD purchasing power parity)	3 800 (2010)
Public financing (% of total expenditure)	68
Private financing (% of total expenditure)	32
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	3.3
Practicing nurses (per 1000 population)	10.1
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	6.7
Hospital discharges (per 1000 population)	159
Total hospital beds (per 1000 population)	3.77 (2010)
Average length of stay, all causes (days)	5.8 (2010)
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	100
Out-of-pocket medical spending (% of household consumption)	3.2

Source: OECD 2013

### 15.3 Gathering Information on the Australian Case

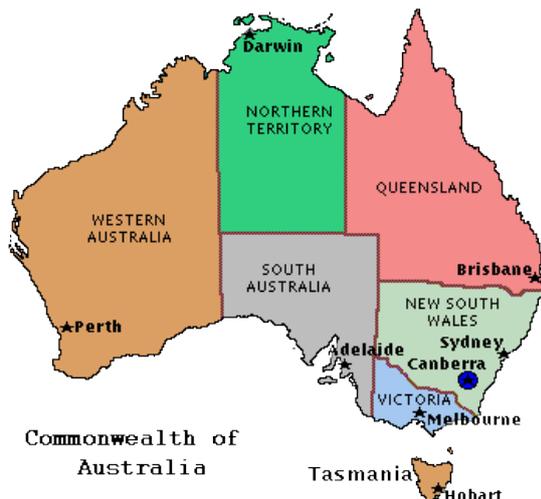
The empirical material for this chapter was gathered through

Desktop research in May-June 2013 and October 2015: Official documents and websites of governmental actors and sector organizations were explored to gather background on the Australian healthcare system, eHealth strategy, key actors and initiatives.

### 15.4 Financing, Governing and Organizing Healthcare

Australia has a federal system of government with three political and administrative tiers; Commonwealth, States and Territories, and local government. States and Territories have their own Parliament and their own constitution; however each State parliament is subject to the national Constitution as well.

A defining character of the Australian federal system is the dynamic tension that is inherent in its intergovernmental relations and the degree of cooperation needed between levels of government. The Australian government collects most taxes, but the States and Territories have a greater role in



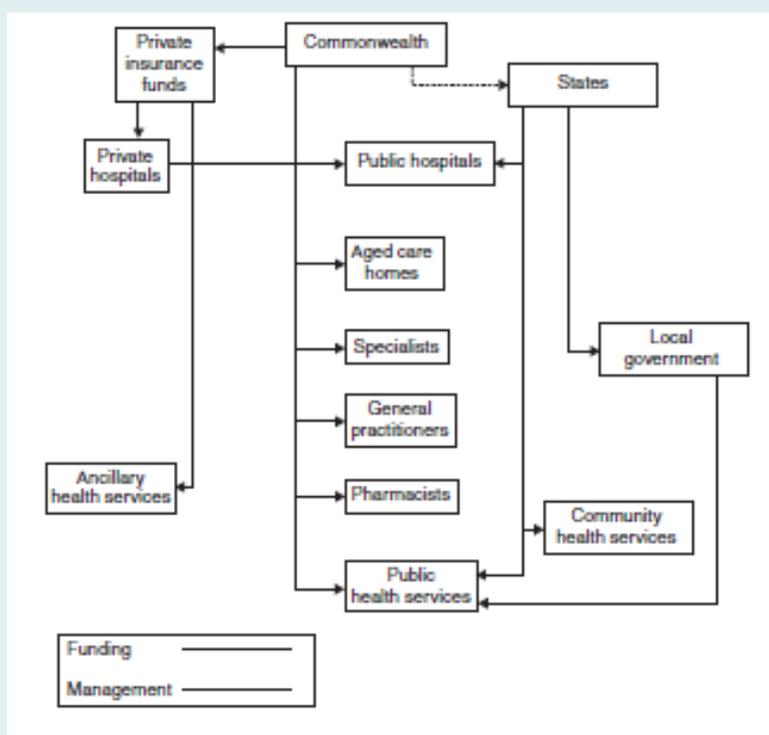
administering services; that is the fiscal and functional responsibility is divided and thus intergovernmental relations involve ongoing negotiations over funding and respective responsibilities.

The Australian healthcare system is one of the country's largest and most complex industry sectors. Healthcare is funded through a combination of payments by the Australian, State and Territory Governments, private health insurance and consumers. Public spending accounts for approximately 68 % of total health expenditure. The rest is paid by individuals,

health insurance funds and workers compensation and compulsory motor vehicle third party insurance providers.

The Australian Government, through the [Department of Health](#) is responsible for policy development, healthcare funding and service regulation. The Australian Government provides funding to State and Territory Governments through Australian Healthcare Agreements (AHCA) to help fund the delivery of public hospital services. It also provides rebates that assist patients to meet some or all of the costs of the medical services provided by independent, private sector providers such as GPs, pharmacists, radiologists, pathologists and private clinical specialists. The Australian Government has responsibility for administering and funding Medicare and the Pharmaceutical Benefits Scheme and for the regulation of the private health insurance industry.

Figure 45. The Australian Healthcare System



Medicare is available to people who reside permanently in Australia and provides subsidized access to doctor of choice, subsidized prescription drugs and free public hospital care.

Healthcare service is delivered via a complex network of public and private sector care providers. The private sector delivers much of the primary care and much specialist medical care, runs private hospitals, and offers most allied healthcare. State and Territory governments run public hospitals which provide services that are free at the point of delivery for all Australians. They are also responsible for delivering a range of community health, mental health, patient transport, dental and public health services, mostly at no charge for consumers. Since 2000, Commonwealth and State governments generally have sought to reduce their role in direct health service delivery and to increase the role of voluntary and for-profit providers.

The majority of physicians are engaged in private practice. GPs provide most primary care. Private medical specialist provide most ambulatory secondary healthcare, but also contract their services to public and private hospitals. Private physicians are key stakeholders in the health sector, and have major influence upon healthcare policies.

Private health insurance funds are also significant players, supported by the Government through major tax rebate on premium.

### ***Healthcare reform***

The Australian healthcare system is facing a number of challenges that poses challenges with regard to the sustainability of the healthcare system. These are similar to those found in most western countries, and include increasing incidence of chronic disease, driving a need for better coordination of service delivery across different parts of the health sector; persistent health inequalities, socioeconomically disadvantaged people, indigenous Australians, and those living in rural and remote areas typically experience relatively poorer health outcomes; an ageing population, leading to increasing demands for healthcare services and a relative decrease in the working age population; new technologies and increasing consumer expectations are a major driver of increased health spending in recent years; a range of health workforce shortages across the sector, especially in rural and remote areas and in indigenous communities.

Healthcare demand, cost and workforce trends and pressures is calling for significant reform. There is a widespread recognition within the sector that better use of information technology should play a critical enabling role in implementing national healthcare reform and policy agendas and improving the efficiency, safety and ultimately the sustainability of the Australian healthcare system. There is also a greater recognition of the role that individuals can play in protecting their health and more actively participating in the care process to improve personal health outcomes. At the same time, broader social trends have increased the demand for, and acceptance of, the use of information technology to meet personal and community needs.

These sentiments, combined with mounting frustration at the severely limited ability to effectively access and share health information, are driving a substantial amount of eHealth activity across all parts of the Australian health sector. Since 2005, the Commonwealth, States and Territories have been investing in key building blocks for a national eHealth platform. At the same time, every

Australian State and Territory is in the process of either defining or implementing some form of jurisdiction-wide eHealth strategy, and making significant investments in foundational infrastructure in the health sector. Within the private health sector, individual clinicians, professional groups and organizations are also investing in eHealth infrastructure and initiatives. The result is a very large and growing number of disparate eHealth initiatives being delivered within local geographic regions, within acute and primary care settings, and across health sector disciplines in this country.

Despite progress towards a national health reform plan, there is a lack of clarity regarding strategic objectives and priorities for healthcare in Australia. This is an issue when attempting to link eHealth to a set of overarching health system goals. Also the very nature of the Australian healthcare system has a number of implications for eHealth. First and foremost the complex and fragmented nature of the service delivery landscape has resulted in the creation of a vast number of discrete silos or islands of information across all parts of the health system which causes significant barriers to the effective sharing of information between healthcare participants and challenges when trying to understand and report what is really happening in the healthcare system.

The complexity of Australia's health funding and accountability arrangements also makes it very difficult to ensure effective collaboration between, and alignment of, the many largely autonomous public and private sector providers of Australian healthcare services. This manifests itself in the lack of a coherent and coordinated national strategy for healthcare which should ideally be in place to guide the development and prioritization of a national eHealth Strategy. The increasing incidence of chronic disease is resulting in a shift from episodic, acute based care to an environment where the vast majority of care is being delivered in community settings. With the strategic emphasis changing to reduce pressure on the specialist sector, there is an increasingly important need to better support primary and community care providers with tools to access and share relevant health information.

### ***15.5 Australian eHealth: Past, Present, Future***

There is a strong support for eHealth in general, among the Australian stakeholder of the healthcare system, and a belief that without more nationally coordinated efforts initiatives will only respond to localised needs and the broader benefits of eHealth on a national scale will not be realized. The inability to leverage and extend successful local initiatives is seen as a result of lack of core infrastructural building blocks.

The significant number of (uncoordinated) ICT initiatives occurring at all levels of the healthcare system entail that different sectors at very different stages of maturity with GPs at the forefront and the specialist sector lagging behind. Lack of enforceable standards for data and interoperability in the health sector has contributed to an environment of uncertainty for IT vendors, which again has led to vendor led eHealth solutions based on proprietary systems with limited flexibility and interoperability.

Since early 2000, there has been an increasing activity at the national level. A national eHealth governance model is established with National e-Health and Information Principal Committee as the Government's strategic advisory body. Work on standards, identifiers and terminologies being driven by NEHTA. Also a significant driver, the Australian Government has funded provision of broadband internet access to over 98 % of Australian businesses and residents.

The vision is for eHealth is that it will; *enable a safer, higher quality, more equitable and sustainable health system for all Australians by transforming the way information is used to plan, manage and deliver healthcare services.*

- Ensure the right consumer health information is electronically made available to the right person at the right place and time to enable informed care and treatment decisions
- Enable the Australian health sector to more effectively operate as an inter-connected system overcoming the current fragmentation and duplication of service delivery
- Provide consumers with electronic access to the information needed to better manage and control their personal health outcomes
- Enable multi-disciplinary teams to electronically communicate and exchange information and provide better coordinated healthcare across the continuum of care
- Provide consumers with confidence that their personal health information is managed in a secure, confidential and tightly controlled manner
- Enable electronic access to appropriate healthcare services for consumers within remote, rural and disadvantaged communities
- Facilitate continuous improvement of the health system through more effective reporting and sharing of health outcome information
- Improve the quality, safety and efficiency of clinical practices by giving care providers better access to consumer health information, clinical evidence and clinical decision support tools
- Support more informed policy, investment and research decisions through access to timely, accurate and comprehensive reporting on Australian healthcare system activities and outcomes.

### ***Timeline***

**1999:** First steps towards implementation of a national eHealth policy were taken with the establishment of a National Health Information Management Advisory Council and its launch of the action plan - *Health Online*.<sup>125</sup> The Plan, and its consecutive 2001 update focus on:

- Data protection and other legal/security issues, standards, infrastructure issues, change management and training, research and development
- Information and services tailored to meet consumer expectations for more information, more choice and a greater say in their own health and well-being.
- Support for clinical care by sharing information with the aim of providing coordinated care, decision-support services and better access to current practice information; efficiency gains through digital data transfer; better clinical and administrative data for research, policy and planning purposes.

**2000:** [The HealthConnect program](#) is launched, a concept for information sharing through the use of standardized electronic clinical messages. Data is to be harvested at the point of care and stored in a

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<sup>125</sup> Health OnLine: A Health Information Action Plan for Australia (1999) (2d ed. 2001) (not available online).

central repository which would give health professionals and consumers access the health record at subsequent episodes of care. Pilot projects were established in three states.

Concurrently ran MediConnect, which aimed to provide an Australia wide electronic medication record. 2004 MediConnect was incorporated into the HealthConnect program. Medicare numbers were to be used to create a personal electronic medical record which linked prescriptions for medications written by different doctors and dispensed by different pharmacies. The system was intended to minimize the incidence of medication misadventure, to be useful in emergency situations and to minimize the practice of doctor-shopping. There were widespread concerns about the privacy issues surrounding the use of BMMS within the medical community. Following field testing, conclusions were indeed that more work needed to be done to include patients and consumers and enhance information security and privacy.

**2004:** A Boston Consulting Group (BCG) report to government advised that a further problem in implementing a comprehensive eHealth program was that there were too many small, loosely coordinated eHealth initiatives underway across the states and territories which were neither interoperable nor scalable. The report recommends establishing a central collaborative body.

Partly in response to this report the [National eHealth Transition Authority \(NEHTA\)](#) is formed. The task of the new body, funded jointly by the state, territory and federal governments, was to advance the national eHealth agenda through development of standards and terminologies, and patient and provider identifiers.

A change in focus for HealthConnect was also undertaken and the program took a new direction as a *change management strategy*. This strategy sought to support state based projects to work towards the national HealthConnect implementation outcomes as outlined above. The program aimed to work towards creating national interoperability and consistency of health information shared via electronic means. The focus of state based projects changed to be more aligned with the local community requirements, abilities and opportunities in the *eHealth* environment.

**2005:** HealthConnect and BMMS are evaluated. The evaluation reports points to lack of infrastructure and connectivity which limits results. The national strategy for EHRs changes:

- Shared responsibility between HealthConnect Program Office and NEHTA. NEHTA in charge with is the development of a security framework for the data that is stored and the way it will be accessed.
- Opt-out model for consent proposed.
- Plans for a Medicare 'smartcard' introduced. Card to contain information such as organ donor status and expenditure data, in addition to providing access to standard Medicare services. An 'opt in' trial of undertaken, but only 1 % of those eligible opted-in and the project is abandoned.

**2008:** In order to meet the challenges of the healthcare system, several commissions are established to explore future possibilities for improving the governing and organizing of healthcare, among those the National Health and Hospitals Reform Commission.

Australian Health Ministers commission Deloitte to develop a [strategic framework and plan](#) to guide national coordination and collaboration in eHealth. The main question addressed is whether to allow

the eHealth activity to progress in an unfettered manner or to take action to more strongly coordinated and aligned activity on a national basis.

Later that year, the Government introduced its [National eHealth Strategy](#), calling for a national strategic framework and plan for national coordination and collaboration to be put in place. The strategy is to develop frameworks and infrastructural components that can be leveraged at State and Territory, regional and local levels to deliver solutions that are able to be integrated and shared data across geographic and health sector boundaries.

**National infrastructure** - Deliver core elements of enabling national eHealth infrastructure once, rather than duplicating development costs and efforts and increasing the likelihood of rework

**Stakeholder engagement** - Actively engage key healthcare stakeholders in the design and delivery of eHealth solutions

**Incremental approach** - Build of long term national eHealth capability in an incremental and pragmatic manner, focusing initial investment in those areas that that deliver the greatest benefits for consumers, care providers and healthcare managers

**Recognizing different starting points** - Balance active support for care providers with less developed capability, while not constraining the ability for more advanced participants to progress

**Leverage** - More effectively leverage and scale eHealth activity across the country

**Balancing alignment and independence** - Drive alignment of national eHealth activities whilst not unnecessarily limiting the ability of healthcare participants and vendors to implement locally relevant solutions

**Relevant skills** - Ensure sufficient numbers of skilled practitioners are available to support delivery of the national eHealth Strategy.

Four major strategic streams are identified:

1. Establish the **core foundations** for electronic information exchange across the health sector.
2. Stimulate the delivery of **eHealth solutions**, specific computing systems and tools, to address the high priority needs of consumers, care providers and healthcare managers.
3. **Change management** to foster consumer, care provider and healthcare manager adoption of eHealth and rapidly achieve a 'tipping point' of stakeholder adoption of eHealth solutions.
4. Establish national eHealth **governance** structures and mechanisms to ensure the effective leadership, coordination and oversight of the national eHealth work program.

**2009:** The final report from the the National Health and Hospitals Reform Commission is delivered; [A Healthier Future for All Australians](#) containing several strong recommendations for eHealth, including the person-controlled electronic health record (PCEHR).

**2010:** The Government allocates \$466.7 million over 2 years for the development of PCEHR, a national EHR solution that gives users access to their medical information stored in different healthcare providers' IT systems via a web-based portal.

The same year the [Healthcare Identifiers Act](#) was passed, paving the way for eID for citizens - a key infrastructure component for eHealth.

**2011:** Implementation plans for the PCEHR moved quickly. The Government releases the *Draft Concept of Operations Relating to the Introduction of a Personally Controlled Electronic Health Records System*, suggesting how the PCEHR system would be likely to look, what information it might contain, and how it might function and connect with existing clinical systems.

**2012:** Government launches [Personally Controlled EHR. The solution is based on an opt-out solution.](#) The PCEHR System Operator is the Secretary of the Department of Health. The eHealth record can include information that is held by the Chief Executive Medicare, within the Department of Human Services.

The Government invests around \$89 million in the Practice Incentives Program to stimulate uptake and support of eHealth in general practice. There are five further requirements for this incentive:

1. Integrating Healthcare Identifiers into Electronic Practice Records
2. Secure Messaging Capability
3. Data Records and Coding
4. Electronic Transfer of Prescriptions
5. Personally Controlled Electronic Health (eHealth) Record System

In addition, time spent on viewing and documenting in PCEHR is recognized for billing in the Medicare Benefits Schedule.

**2013:** the Government releases a [review of the PCEHR](#) which looks into concerns about progress in implementing the PCEHR system, in particular problems with the opt-in approach, the need to target specific user groups such as chronic care patients, and the completeness and quality of data.

**2015:** Responding to the challenges identified in the 2013 review, several changes are introduced:

- PCEHR changes name to “MyeHealth Record”.
- Changing the opt-in model to an opt-out system.
- NEHTA is dissolved and an oversight agency will be put in its place called the Australian Commission for eHealth that will have a variety of sub-committees reporting to it.

## **15.6 Current Australian eHealth system**

### **15.6.1 Infrastructure**

The eHealth record is a voluntary 'opt-in' system. It does not replace the records that GPs hold or the way they communicate with their patients. Rather it provides a summary of key medical information that can be very useful for other clinicians. The eHealth system facilitates the secure sharing of that information in a way that is controlled by the patient.

Health information used by the PCEHR is stored in a network of connected systems. The system is based on the XDS (Cross Enterprise Document Sharing) Profile published by IHE (Integrating the Health Enterprise). However, the usual IHE Patient Management system (PIX/PDQ) has been replaced by an individual healthcare identifier service being assigned to participants and the option of masking and limiting information available for viewing controlled by the patient or a nominated

representative (see below for more information). In addition the usual authentication and security IHE profiles have been replaced by, or significantly modified to work with, existing infrastructure. HL7 CDA format is used to transfer information between different healthcare clinical systems whilst still allowing information to be accessed and viewed. The [Secure Message Delivery \(SMD\)](#) is a set of specifications developed collaboratively by the eHealth community including NEHTA, Standards Australia, Desktop Software vendors and secure messaging service providers. This set of specifications defines an approach to eHealth communication using widely supported IT industry standards. The SMD specifications support the secure delivery of messages containing clinical documents and/or other information between healthcare organisations, either directly or through one or more messaging service providers.

In addition to having a secure messaging connection, sending and receiving clinical systems need to be conformant to message format standards. NEHTA has defined Clinical Document Architecture (CDA) standards for [eReferrals, Specialist Letters and Discharge Summaries](#). This allows the exchange of these document types using secure messaging. Over time NEHTA and other bodies may define conformance assessment processes for additional document types.

The PCEHR uses both [the Orion Health Clinical Portal and Patient Portal](#). A Healthcare Provider Organisation that is registered for the eHealth record system can access information from the national system via their local clinical information system.

#### 15.6.2 Infostructure

As part of the development of the PCEHR, NEHTA undertook an audit of the existing use of messaging standards throughout the healthcare sector. This showed that by far the most widely used standard was v2.x. It therefore concluded that whatever approach to eHealth interoperability was adopted, which would ultimately lead to a national EHR, it would need to accommodate migration from v2.x if it was to be able to retain the significant investment in existing systems and be future-proofed against whichever of the competing standards available at the time (2007) became the international norm.

The choice was between ISO CEN 13606, OpenEHR or v3 messaging with CDA. Its recommendation was to continue with the use of v2.x messaging as the primary means of exchanging health information in areas where it is currently delivering benefit until superseded by v3 messaging and CDA.

The [NEHTA Standards catalogue](#) consists of a collection of standards and specifications that are essential guidance for those who develop, sell, support, buy and implement e-health software in Australia. The catalogue provides a list of the standards recommended by, and specifications sourced or developed by, NEHTA. The catalogue also provides advice on when and where the use of a standard is appropriate.

NEHTA also makes available [a clinical reference platform](#) - a clinically validated technical simulator for eHealth, with technical services and sample code supporting demonstration, training and development testing.

SNOMED CT has been endorsed by the Australian state and territory governments and identified as the preferred national clinical terminology with a constrained set of LOINC codes used for pathology requests and results for Australia.(42) ICD 10-AM is used for coding of inpatient episodes.

The primary standards adopted in Australia include:

- HL7 v3 messaging and CDA for all new initiatives with continued use of v2.x where established
- SNOMED CT, LOINC and ICD 10-AM standards are the terminology and classification systems in use.

The National Clinical Terminology and Information Service, part of NEHTA, is responsible for managing, developing and distributing terminology to support the eHealth requirements of the Australian healthcare community. This responsibility extends to licensing SNOMED CT on behalf of IHTSO. NEHTA's clinical terminology solutions include: SNOMED CT-AU and Australian Medicines Terminology (AMT). NCTIS has a dedicated Product Support team to assist licence holders in their understanding and implementation of SNOMED CT-AU and the AMT.

### 15.6.3 Privacy, Information Security, Access Control

The [individual healthcare identifier](#) service is a national system for uniquely identifying healthcare providers, healthcare organisations and individuals receiving healthcare:

- **Healthcare Provider Identifier – Individual** for individual healthcare providers involved in providing patient care
- **Healthcare Provider Identifier – Organisation** – for organisations that deliver healthcare (such as medical and allied health practices, or hospitals); and
- **Individual Healthcare Identifier** – for individuals receiving healthcare services.

Healthcare Identifiers can only be used for the purposes described in the [Healthcare Identifiers Act 2010](#) and [Healthcare Identifiers Regulations 2010](#), e.g. for communicating and managing healthcare, which covers documents and processes such as electronic referrals, discharge summaries and medication management.

[National Authentication Service for Health \(NASH\) Public Key Infrastructure \(PKI\)](#) is required by healthcare providers through their healthcare provider organizations to access the PCEHR system and send electronic messages. The record system entrusts a participating organization to grant access to 'authorized users.' An authorized user must be an employee who has a legitimate need to access the eHealth record system as part of their role in healthcare delivery. When authorized users access the eHealth record system, they are only permitted to access the records of patients with whom they are involved in delivering healthcare services. All access to the eHealth record system is with the patient's initial consent and is audited.

All clinical documents in the eHealth record system will be accompanied by document source information stating where, when and by whom the document was created. All clinical documents will also be digitally signed by the provider organization to ensure they have not been modified since they were submitted.

Citizens choose whether or not to register for a PCEHR. Registration can be done online, by phone, in person during visits to a service provider, or through a registration application form.

In order to use the PCEHR the patient must first provide consent when registering or at any time afterwards. Authorized representatives can provide consent on behalf of dependant(s). People with parental responsibility can consent to their children registering for a PCEHR. Once documents are included in an eHealth record, they are visible to **anyone** who is authorized to access the eHealth record.

Once consent is provided, the Chief Executive Medicare will notify the System Operator which documents are available. Some of the information from each available document will be uploaded to the eHealth record system. The eHealth record system will always link to the original document held by the Chief Executive Medicare.

Registering for an eHealth record involves proving or verifying identity by an identity verification code – IVC. Patients will then receive a login and password for further use of their PCEHR.

In life-threatening cases where it is unreasonable or impractical to obtain consent to access a patient's record, healthcare providers at participating Healthcare provider organizations may assert emergency access for five days.

Citizens control what is in the PCEHR, and are able to remove a document or information about prescribed medications or other treatment from the record, including the record as a whole. It is possible to restore documents that were previously removed. It is also possible to restrict personnel from viewing any or all of the record. This ability to set access control measures is a key privacy feature of the PCEHR system.

Patients can read everything in full that is added to their record. Healthcare personnel may choose to include additional information in their local clinical information system that is not included in the eHealth record. In any event, patients have a right under the Privacy Act 1988 to access the personal information that healthcare providers hold about them. The citizens have access to a log over who access the record.

When a document is uploaded to the eHealth record system, it will be retained for 30 years after the individual has died, or, if the date of death is unknown, for 130 years after the document was first uploaded.

The PCEHR System is supported by a legislative framework that includes governance arrangements, privacy and security framework, and a registration regime:

- Personally Controlled Electronic Health Records Act 2012
- Personally Controlled Electronic Health Records Regulation 2012
- PCEHR Rules 2012
- PCEHR (Participation Agreements) Rules 2012
- PCEHR (Assisted Registration) Rules 2012

#### 15.6.4 Shared eHealth Components and Services

The eHealth record system provides an active online record that follows patients as they move through Australia's health system, and includes three sets of information – clinical, Medicare and personal. As clinical software is updated to communicate with the eHealth record system, more clinical information can be added by healthcare providers. Examples of documents that may be included in an eHealth record are a:

- **Shared Health Summary** includes information about medical conditions, medications, allergies, and family medical history. The structure is underpinned by the Royal Australian College of General Practitioners template for a GP health summary.
- **Event Summary** of a significant consultation can be uploaded by a healthcare provider at any participating healthcare provider organization that is authorized to use the record system.
- **Hospital Discharge Summary** can be uploaded by healthcare providers involved in the patient's hospital care.
- A copy of a **Specialist letter** may be uploaded to the eHealth record system.
- A copy of a **eReferral Letter** may be uploaded to the eHealth record system.
- **Prescription and dispensing information**, including dose and directions for consumption, can be uploaded to the eHealth record system.
- **Patients personal information and notes**, the latter is not accessible for healthcare personnel.

To maintain the integrity of the system, information uploaded to the eHealth record system, including medications, cannot be altered or edited (unless the patient has authored or uploaded the information). The system requires a new document to be uploaded by the authoring healthcare provider so, while the old version will still be visible, the uploaded document will take precedence.

[Electronic Transfer of Prescriptions](#) is an application for local EMR systems which creates and sends electronic prescription information (ePrescriptions). These electronic script copies will be sent to a Prescription Exchange Service (PES) where they are stored and can be retrieved later by a dispenser at the time of dispensing.

If a patient has an eHealth record and their healthcare provider is using Electronic Transfer of Prescriptions (ETP) and is registered with the eHealth record system, a copy of the prescription information will flow through to the eHealth record system via the PES and be visible in the Prescription and Dispense View. Similar to prescribers, dispensers, through their updated software, will be able to send dispense information to the PES and onto the ehealth record system where it will be visible in the Prescription and Dispense View. The [Prescription and Dispense View](#) in the eHealth record system allows individuals and their healthcare providers to easily view details of their prescribed and dispensed medications. The view displays the name and date a medication has been prescribed and dispensed (both the brand name as well as the active ingredient/s), the strength of the medication (e.g. 2mg, 20mg, etc.), the direction for consumption (e.g. take one capsule daily) and the form of the medication prescribed (e.g. capsule, tablet, inhaler, etc.). Over time, the view will capture the history of a patient's medication details. Through this approach, all authorised healthcare providers, i.e. not just the prescriber and dispenser, will be able to view patients' prescription and dispense information through the eHealth record system.

### 15.6.5 EHR Landscape

EMR penetration in 2012 was estimated at 66 % for both hospital and ambulatory systems segments combined. For the Asian Pacific regions as a whole Siemens, Cerner, Allscripts and InterSystems held over 15 % share of the market each, with NEC, Fujitsu, MediTech and CSC Healthcare making up the rest.

### 15.6.6 Digital Services for Citizens

Citizens can apply for and view their PCEHR on a device of their choosing, as long as it has internet access.

A mobile app is available to access the Child development component of the citizen's child's eHealth record - *my child's eHealth record* and enables the user to enter and view the growth and development information on a smartphone.

## 15.7 Secondary use of data

Visitors seeking general information about the health of the Australian population or its health services and institutions are referred to [Australia's Health 2012](#), the comprehensive health flagship publication of the Australian Institute of Health and Welfare (AIHW).

Australian health statistics is coordinated under the National Health Information Agreement. The Agreement's structures and processes ensure that consensus-based standards apply to national aggregations, for consistent and high quality data. Details are available on the [AIHW Data Standards](#) web page. Australia's national health and welfare metadata registry, [METeOR](#), is a key enabling tool.

The national statistics agency, Australian Bureau of Statistics (ABS), is the principal source of information about population health and demography, and has an extensive range of publications derived from its regular population survey program, 5-yearly censuses of population and housing and other sources.

The Australian Commission on Safety and Quality in Health Care, the NHMRC Centre of Research Excellence in Patient Safety and the National E-Health Transition Authority (NEHTA) have collaborated to develop [operating principles and technical standards](#) for Australian Clinical Quality

Registries. A [Framework for Australian Clinical Quality Registries](#) has also been developed in collaboration with the states and territories and expert registry groups. The Framework describes national arrangements for clinical quality registries.

## 15.8 Final reflections

Despite widespread use of modern technology in general practice and community pharmacy, Australia's healthcare system lags behind all other sectors of its economy in the use of computerized systems. Currently, Australia sits in the middle in rankings of health systems among industrialized

nations, and the use of modern electronic technologies for communication and clinical information transfer within health systems is low.<sup>126</sup>

[The 2014 Government review of the PCEHR program](#) pointed to 38 recommendations to improve the existing system. Among the most important were:

### ***Challenges recruiting users***

After three years, only 2 million people had registered for a record. Even as increasing amount of content was put into the system, participation rates remained flat. The opt-in approach had also made it difficult to reach those patient groups for which the record system was intended to have specific potential, such as those with chronic medical conditions or those living in remote areas. The opt-out solution introduced in 2015, means privacy and security of records should become an even stronger priority for all users and a need to implement measures for developing understanding of how the privacy and security works for consumers and practitioners.

### ***Challenges related to usability and reliability in actual clinical settings***

Development of and compliance with standards are critical for adoption of any federated system or process. Common terms and language, IT protocols and report structures will improve integration and application, however standards should be developed with current workflows in mind and using accepted and tested methods for development. Usability of the system at all stages of engagement from registration to reinstatement and the process for identifying and addressing usability issues. This includes ensuring system interaction is designed to be part of a standard workflow of events. The lack of integration between current systems, a single sign on and ease of navigation between health applications were seen as significant inhibitors to use of the PCEHR.

The report also pointed to a problem with the maximum amount of data allowed into the system. Many chronically ill patients who had worked hard to get their doctors to use the record found it quickly became full allowing no more medical entries because it had a limit of 1.000 entries. In addition, records were not populated with clinically usable information. Data sets are unreliable or incomplete, and the liability and indemnity that flows from this. In some cases, the medical information uploaded to the records by the government proved incorrect.

Overall, the record system was criticized for its “scrap book” approach to clinical record. There is no guarantee that all the health professionals involved in the care of a patient will participate and supply information, or that that information will be complete. This is further complicated by the tension between the principle of a citizen controlled model, which allows the citizens to delete or withhold documents from the record, and clinicians who are concerned with data completeness and accuracy. The result was by critics a system with inherent extensive clinical risks associated to its use.

As noted by Pearce and Haikerwal<sup>127</sup>, Australian general practice has computerized rapidly, due to the combination of *need* (increasingly complex prescribing regulations), some financial *incentives*

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<sup>126</sup> <http://www.ncbi.nlm.nih.gov/pubmed/18657471?dopt=Abstract>

(the federal government's Practice Incentives Program for GPs), the availability of relatively affordable software packages, reduced hardware costs, and *support* through divisions of general practice. GP now enjoys an almost complete uptake of EMRs. However, GPs have no mechanism for securely sharing electronic information, despite the incentive program encouraging the use of PKI to encrypt information. Further, although the business case for e-health is clear on efficiency grounds, there is no mechanism to encourage the use of this accessible, accurate and historically rich body of data for quality purposes.

The problems in hospital practice are different, mainly because of scale and the level of disconnection between those who use electronic tools for their work (patient care, research, planning, measuring and evaluating) and those who provide funding (local, regional, state and federal managers and legislators). The uncoordinated implementation of differing, incompatible systems within hospitals, between hospitals in a region and across boundaries compounds a dire lack of national coordination and so loses the benefits of drawing on expertise and knowledge across the nation. The need–incentive–support triangle that was so effective in GP is unbalanced in the hospital system. Most programs that look for hospital-wide adoption of eHealth underestimate the cost of change management. They also suffer from lack of infrastructure and historical underfunding of ICT. Simple processes, such as using computerized physician order entry, reducing drug usage and improving safety, can often increase efficiency in a single setting. However, applied across the hospital system, these often increase the workload of “point-of-care” staff as they comply with computer-regulated protocols. Exploiting the potential of ICT in the hospital sector requires access to and training in the technology used.

The issues for governments are different again, because they need to balance the funding expense against the requirements of an electorate or stakeholder groups. Unlike GPs and hospitals, governments need to account for the interactions between healthcare providers. Given that modern healthcare is all about team-based care, this connectivity is an important feature, and a benefit that is often not realized within a single sector. The potential benefits from connectivity are large, coming from fewer tests and reduced adverse outcomes. The conundrum for governments is that they must outlay significant funding initially, in order to reap benefits that accrue into the future.

As has been shown by the Australian researcher Coeira<sup>128</sup>, Working from the top down is difficult, inflexible and prone to poor uptake. Building from the bottom up is haphazard and, without a national standard to unify effort, wasteful and ineffective. An alternative strategy is a “middle out” approach, in which governments build on and encourage existing functional (but outdated) legacy systems, and adopt a national standard with the intrinsic building blocks for the future (individual EHRs, eHealth services, eHealth solutions and national infrastructure components). The difficulty is that benefits will only accrue when a critical mass of the system is digitized and connected — in the future.

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<sup>127</sup> <http://www.ncbi.nlm.nih.gov/pubmed/20919969>

<sup>128</sup> <http://www.ncbi.nlm.nih.gov/pubmed/19407078?dopt=Abstract>

Pearce and Haikerwal note that a middle-out approach, focusing on local flexibility in choice of systems and building national infrastructure and standards, is highly dependent on matching the national role of framework and standard developing actors as NEHTA with a national implementation arm, with the ability to coordinate across the states and territories, and across the myriad private providers that administer the bulk of healthcare. To ensure the clinical relevance, utility, safety and acceptability of eHealth systems, health professionals urgently need technical capacity and expert guidance.

When it comes to the ongoing development and introduction of the MyeHealth record, the pivotal question, according to Coeira, is whether a summary care record is at all a sensible approach to improving coordination of care, or whether a shared record only makes sense, when it is a fully distributed and shareable clinical record.<sup>129</sup>

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<sup>129</sup> <http://coiera.com/2013/11/29/submission-to-the-pcehr-review-committee-2013/>

## 16 New Zealand

### 16.1 Demographic Data and Political Tradition

Population (2013)	4 470 800
Area (km <sup>2</sup> )	268 021
Political tradition	Unitary parliamentary constitutional monarchy
Administrative levels	State, council

### 16.2 Key Figures for Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	80.9
<b>Expenditure on health</b>	
In percent of GDP	10.3
Per capita (EUR purchasing power parity)	3 182
Public financing (% of total expenditure)	82.7
Private financing (% of total expenditure)	17.3
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	2.6
Practicing nurses (per 1000 population)	10
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	3.7 (2012)
Hospital discharges (per 1000 population)	147
Total hospital beds (per 1000 population)	2.8
Average length of stay, all causes (days)	8.6
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	100
Out-of-pocket medical spending (% of household consumption)	1.8

Source: OECD 2013

### 16.3 Gathering Information on the New Zealand Case

The empirical material for this chapter is gathered through desktop research in May-June 2013 and January-March 2015. Official documents and web sites of governmental actors and sector organizations were explored to gather background material on the healthcare system in New Zealand, eHealth strategy, key actors and initiatives.

In addition, in June 2013 a meeting was arranged with Dr. Murray Milner, Board Director for the National Health IT Board in New Zealand during his visit to Norway.

The description that follows is not exhaustive. The content of this report reflects the knowledge needs of the Norwegian *One patient – One record* program.

### 16.4 Financing, Governing and Organizing Healthcare

The Minister of Health develops policy for the health and disability sector and provides leadership. [The Ministry of Health](#) leads New Zealand's health and disability system, and has overall responsibility for the management and development of that system. [The New Zealand Health](#)



Strategy provides the framework within which actors across the health sector will operate. It highlights the priorities the Government considers to be most important. Those priorities reflect diseases such as diabetes and cancer as well as factors that influence health such as smoking and nutrition.

Most health services are publicly funded, by means of general taxation. Other significant sources include local governments and out-of-the-pocket payments. The Ministry of Health allocates more than ¾ of the public funds it manages to DHBs, who use this funding to plan, purchase and provide health services, including public hospitals and the majority of health services within their areas.

Most of the remaining public funding provided to the Ministry (19 %) is used to fund national services, such as disability support services, public

health, specific screening programs, and mental health services.

Health services in New Zealand are delivered by a complex network of organizations and people. District Health Boards were created in 2001 with the objective of placing responsibility for hospital and community-based health services under the same organizational structure. Today, most of the day-to-day business of the system is administered by the **20 District health boards (DHBs)**. DHBs plan, manage, provide and purchase health services for the population of their district to ensure services are arranged effectively and efficiently for all of New Zealand. This includes funding for primary care, hospital services, public health services, aged care services, and services provided by other non-government health providers including Māori and Pacific providers. The structural reform intended to turn the New Zealand health system into a primary care driven system with primary health organizations at the forefront of service delivery.<sup>130</sup>

Most GP and specialist practices in New Zealand are private. Public hospitals are owned and funded by DHBs. Disability support services and some health services are funded and purchased nationally by the Ministry of Health. DHBs are governed by a board of up to 11 appointed and elected members. DHB boards set the overall strategic direction for the DHB and monitor its performance.

The objective of the DHBs includes:

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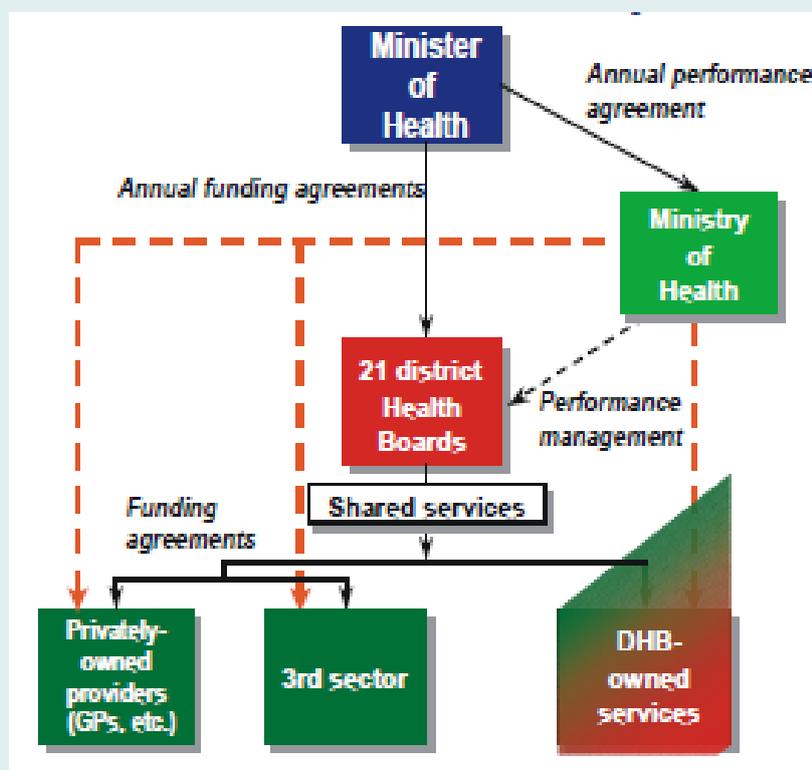
[http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2010/Aug/1434\\_Protti\\_electronic\\_med\\_record\\_adoption\\_New\\_Zealand\\_intl\\_brief.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2010/Aug/1434_Protti_electronic_med_record_adoption_New_Zealand_intl_brief.pdf)

- improving, promoting and protecting the health of people and communities
- promoting the integration of health services, especially primary and secondary care services
- seeking the optimum arrangement for the most effective and efficient delivery of health services in order to meet local, regional, and national needs
- promoting effective care or support of those in need of personal health services or disability support.

There is a range of educational and research institutions involved in the provision of services and training of the workforce. There are also many consumer bodies and non-government organizations that provide services and advocacy for the interests of different groups, and more formal advocacy and inquiry boards, committees and entities. This network of organizations is linked through a series of funding and accountability arrangements to ensure performance and service delivery across the health and disability system.

[The National Health Board](#) is responsible for funding, monitoring and ensuring the sector is compliant with accountability expectations. It ensures compliance with health regulation by Health and other sectors, such as local government. It advises on the current performance of the sector, areas where targeted effort may be required, and trends in performance indicators and service expectations. In general, New Zealand has had a strong focus on formulating [health targets](#) and measuring these through use DHB performance indicators.

Figure 46. The New Zealand Healthcare System



Source: WHO, HiT Series

### **Demographics challenges and ongoing policy reform**

In general, the population has high expectations towards the quality of healthcare delivery. At the same time, the healthcare sector faces challenges regarding an ageing population and an increase in chronic conditions. What is more, in a situation of global competition over highly skilled healthcare personnel, the healthcare system in New Zealand experiences recruitment problems

Looking to the rapid development of ICT, New Zealand is searching for means to realize the potential of health IT in order to develop supporting, enabling and, in some cases, more sustainable solutions for the future of healthcare. This strategy includes giving patient access to health information in order to stimulate more active ownership for own health and treatments.

The Ministry is actively encouraging investment in models of care and services that efficiently meet individuals' needs. eHealth solutions are introduced to enable integration of services across hospitals and communities to put consumers' needs at the center of how care is provided, for instance multidisciplinary teams providing community-based care.

New Zealand has a strong focus on developing a national knowledge economy, in which ICT is a main priority area. This includes developing a national export market for eHealth.

### ***16.5 eHealth in New Zealand: Past, Present and Future***

New Zealand is described as a world leading eHealth country.<sup>131</sup> Beneficial conditions are in place such as high degree of IT maturity on the population; National patient registry since 1980; standardized clinical pathways, regional test result repositories, and a series of eHealth strategies.

New Zealand has had primary care EMR systems in place for 20 years and has steadily expanded and refined them.<sup>132</sup> Regional hospitals began buying PAS in the early 1980s. Specialized applications were added over time, including clinical intranets that linked organizational components together to create a single patient view. Nearly all providers make extensive use of electronic messaging services to exchange clinical information. Currently, electronic communication with patients is beginning to occur via use of EHR systems with patient portals that enable patients to access limited subsets of their records from home.

Most health IT investment has been provided by the government, 21 regionally based district health boards, and occasionally via targeted payments to PHOs. The Ministry's Information Directorate controls an annual budget of approximately US\$65 million, from which it runs a number of central systems and administers the standard process.

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<sup>131</sup>

[http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2010/Aug/1434\\_Protti\\_electronic\\_med\\_record\\_adoption\\_New\\_Zealand\\_intl\\_brief.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2010/Aug/1434_Protti_electronic_med_record_adoption_New_Zealand_intl_brief.pdf)

<sup>132</sup>

[http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2011/Nov/1565\\_Gray\\_electronic\\_med\\_records\\_meaningful\\_use\\_intl\\_brief.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2011/Nov/1565_Gray_electronic_med_records_meaningful_use_intl_brief.pdf)

The government has played a role in developing and fostering health IT by implementing a unique national patient identifier system in 1992, developing a health information privacy code and security framework, creating standards and adopting the HL7 electronic messaging standard, and requiring that claims for payment be made electronically. Governmental policy also created an investment climate for private health IT providers.

Today, healthcare service providers take part in funding eHealth investments out of operating budgets while conforming to centrally directed guidelines and national standards.

Notwithstanding its successes, the New Zealand eHealth system is also demarked by challenges. While each and one EHR system might in itself be patient oriented, there is currently no system in place to provide a coherent overview of patients' medical history.

In the following, we shall take a closer look at New Zealand path towards creating a national eHealth system, and the strategic choices throughout. The initiative for this policy development has come from the District Health Boards, largely as a consequence of their enlarged responsibilities for primary healthcare that have emerged from the healthcare restructuring and establishment of DHBs in 2001. The impetus for change is the DHBs' collective frustration with the inadequacy of their information systems in an environment that calls for better integration of care.<sup>133</sup>

Opting for a distributed, interoperable EHR framework, New Zealand is now building on its existing clinical messaging systems to develop more advanced capabilities that will have widespread use across health system. Key objectives include developing systems that will increase patients' ability to manage their own healthcare and improving the coordination of long-term care for patients with chronic illnesses.

### ***Timeline***

**1992:** The director-general of health appoints a deputy director-general for health information who implements a number of key strategies, including creating a national health index, which provided the sector with a unique individual patient identifier; and implementing a health information privacy code. Additionally, the government actively encouraged the private sector to develop and sell electronic services. These three strategies combined very effectively to support the development of New Zealand's health IT infrastructure.

The same year, the Ministry approves the formation of four value-added networks (VANs) for the healthcare sector.<sup>134</sup> Among these was HealthLink which today is the main infrastructure provider in the sector. With the arrival of the Internet, Public key infrastructure (i.e., digital signatures) became widely used to authenticate users.

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<sup>133</sup> For an overview of the background for, and initiation of the national eHealth project, please see: [http://hpm.org/en/Surveys/The\\_University\\_of\\_Auckland\\_-\\_New\\_Zealand/13/Patient-centred\\_electronic\\_health\\_records.html](http://hpm.org/en/Surveys/The_University_of_Auckland_-_New_Zealand/13/Patient-centred_electronic_health_records.html)

<sup>134</sup> A value-added network is the pre-Internet term for a private communications network that is used by a number of organizations in an industry group)

**2001:** The government launches a healthcare information management and technology strategy that sought to integrate the health sector and facilitate national adoption of EHRs.<sup>135</sup> However, lack of central coordination and governance, led to a situation of information silos as each healthcare purchaser and provider developed their own EHR with no interoperability between the systems.

**2005:** Health Information Strategy Steering Committee releases [Health Information strategy for New Zealand](#). The strategic choice is for a distributed eHealth system, with local autonomy in choice of system, within nationally determined interoperability standards.

**2009:** The DHBs, who are in charge both of primary and specialist care, but nonetheless not able to share health information between its enterprises, issue strong concerns for the future of healthcare. The government announces plans for a national strategy, and engages in an assessment of national vs. regional strategy. Conditioned by the aims of an eHealth system that should be realizable, deliverable, quality oriented and sustainable the conclusion was that regional solutions are better for supporting innovation and competition. The following points were highlighted (please see appendix 5 in [the Health IT Plan](#) for complete arguments):

- Regional governance is more likely to succeed
- eHealth systems do not yet have proven scalability
- Security and privacy of patient information is more easily controlled
- There is support for regional patient flows around regional tertiary centers
- Regional solutions support innovation and competition
- Regional implementation will be faster
- Regional implementation creates significant opportunities for economies of scale
- Some systems are best run nationally

The government establishes [the National IT Board - NHITB](#) and gives it responsibility to develop a national Health IT plan (including an IT architect framework). The plan should take the national healthcare strategy – with its focus on quality and patient safety - as its starting point, using shared access to key clinical data independent of time and place as the main tool. The work should be conducted in broad collaboration with the sector.

Supported by the Government which want to stimulate a national export market for eHealth solutions, , a large group of health IT vendors form an industry association known as the Health IT Cluster (today the group is called [New Zealand Health IT](#)). The cluster provides a forum for vendors and a consultation mechanism for government to liaise with when setting policy.

**2010:** The national Health IT plan is published; [Enabling an integrated healthcare model](#). The Plan directs priorities and investments in eHealth for the upcoming five years. Quality and patient safety are highlighted as the main aims, and shared digital access to key data for patients and professionals, independent of time and place is the tool.

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<sup>135</sup> WAVE Advisory Board. *From strategy to reality: the WAVE project*. Wellington: Ministry of Health; 2001

Responding to the identified challenges of information silos, the strategy lays out a bottom-up/distributed eHealth system in which the regions define the needs while the national level implements a shared, secure and transmittable EHR through use interoperability standards.

A rich set of modules, with clearly defined roles and interfaces between them, is to be built based on a design that is flexible towards changing needs and demands.

- Public health and shared care functionalities are to be delivered as national solutions.
- Clinical support, clinical management and patient administration systems should be delivered as regional solutions.
- Enterprise support solutions to be delivered as one or two national installations.
- Infrastructure should be delivered as a mixture of local, regional and national components, according to the same technical and operative standards.
- Knowledge management delivered via a consistent approach to web pages for the sector overarching clinical innovation, clinical pathways, and sources for health information.
- Shared care records for maternity care and long term care (including home-monitoring) will be developed nationally.

A [Sector Architecture Group](#) is established to develop a shared architecture for national and regional information systems and infrastructure.

Four broad work packages are introduced for which the regions are given the responsibility to operationalize according to their specific needs and capabilities.

1. [eMedicines Program](#) including services such as ePrescription, eMedicine reconciliation, and a database of medicinal information.
2. [Shared Regional Information Platform](#) for the DHBs to support patient administration and clinical information. The aim is to reduce complexity by reducing the total number of installations of every application, and thereby the number of interfaces that needs updating and maintenance.
3. Includes solutions such as [eReferrals, Clinical Data Repository](#) and Clinical Workstation and PAS. National solutions for example for cancer information, Health Identify Project and [Finance Procurement Supply Chain](#).
4. Clinical Integration Initiatives focusing on shared care through Patient Portals, and Maternity records, and a Summary view of primary health information

The overall governance of the National Health IT Plan is the responsibility of the NHITB. New Zealand has experienced challenges of lack of prioritization of IT among healthcare leaders, which has resulted in unwillingness among healthcare personnel to engage in IT projects. Therefore, NHITB has also developed a model for distributing accountability in the implementation of the plan:

[Primary Healthcare IT Governance Group \(Patients First\)](#): a collaborative network with the purpose of strengthening collection, use and dissemination of health information across primary care sector. Will focus on the primary care service need operations and perspectives in the implementation of regional and national initiatives.

**DHB CEO Information Group**: represents the DHBs and coordinates their response to the plan, governance changes and needed actions for increasing capacity to act. Will be responsible for

delivering key projects, including regional clinical data repositories, regional platform for secondary and tertiary systems and fundamental infrastructure projects. The regions are held accountable through their regional service plans, which provide an integrated approach to delivering health services within the DHB's region, underpinned by IT, workforce and new buildings and facilities. Each region has a CEO representative on the NHITB, and a regional IT lead and a portfolio manager on the Sector ICT Implementation Group. This approach is improving the planning and decision-making in relation to IT investment at the regional level, increasing clinical involvement and providing better alignment of regional initiatives with national priority. [Regional progress Readiness Assessments and Systems Landscape diagrams](#) have been created for each DHB region. The baseline measures were first established in 2010.

**Ministry of Health Major IT Projects Committee:** prioritizes Ministry of Health capital expenditure and oversees the delivery of new national infrastructure projects, including the Health Identity program and changes to claims and payment systems. In addition, the Ministry of Health participates as a national provider of health information services and infrastructure. As national contracts mature and new sector-led systems move into operational service, the Ministry will have a role in ensuring their ongoing management and operational governance. It has developed a Ministry of Health IT Plan, outlining its own priorities and changes to support the sector and the goals of the *National Health IT Plan*. The Ministry's IT Plan describes priority developments in areas such as:

- i. health identity services – extend web-service-delivered identity services to all major sector systems
- ii. payment services – migrate obsolete systems to a modern rule-based payment management system
- iii. patient journey measurements – measure the patient's journey through hospital-based services, from receipt of referral to discharge

In [2011 Towards Better Access to Information About Our Health](#) and [2013 Sharing Health Information: Towards better, safer care](#) the Ministry publishes eBooklets to account for the status thus far, and give example of how the eHealth implementations are changing healthcare practice.

**2013:** [National Health IT Plan Update](#) is published, introducing a sharpened focus on the patients' digital access to health information and identifying three barriers for progress.

**Governance** - The DHB sector needs to continue developing effective regional governance models in order to agree on the regional ownership of assets and contracts, and to priorities regional and national IT investment ahead of local initiatives, This requires reconfiguring hardware, software and people resources into a regional entity, governed and funded by DHBs.

**Funding** – The healthcare sector funders need to continue to make long-termed investments in IT as a strategic asset and not make such investment subject to short-term funding constraints.

**Capability** - Some vendors are slow to align with the Plan's direction and programs of work. The widely used legacy applications are difficult and expensive to change and need to be upgraded or replaced. There is a scarcity of IT skills and leadership to advance programs of

work quickly and effectively. Skills need to be built among end-users in order to harvest the benefit of ICT investments.

### **Investment model for eHealth**

Most healthcare organizations, including general practices, specialist practices, PHOs, and all private hospitals, are expected to fund their HIT investment out of their operating budgets, while conforming with national guidelines and standards. It is not uncommon for healthcare provider organizations to make significant investments in health IT.

GP practices in New Zealand are privately owned organizations, which purchase and maintain their own EHR systems and hardware infrastructures. They purchase various electronic services, including technical support services.

The government pays HealthLink for the services it uses to communicate with GPs. Other HealthLink services are paid for by the healthcare providers that use them (e.g., labs, hospitals, and general practices). Fees are calculated on a “user pays” basis.

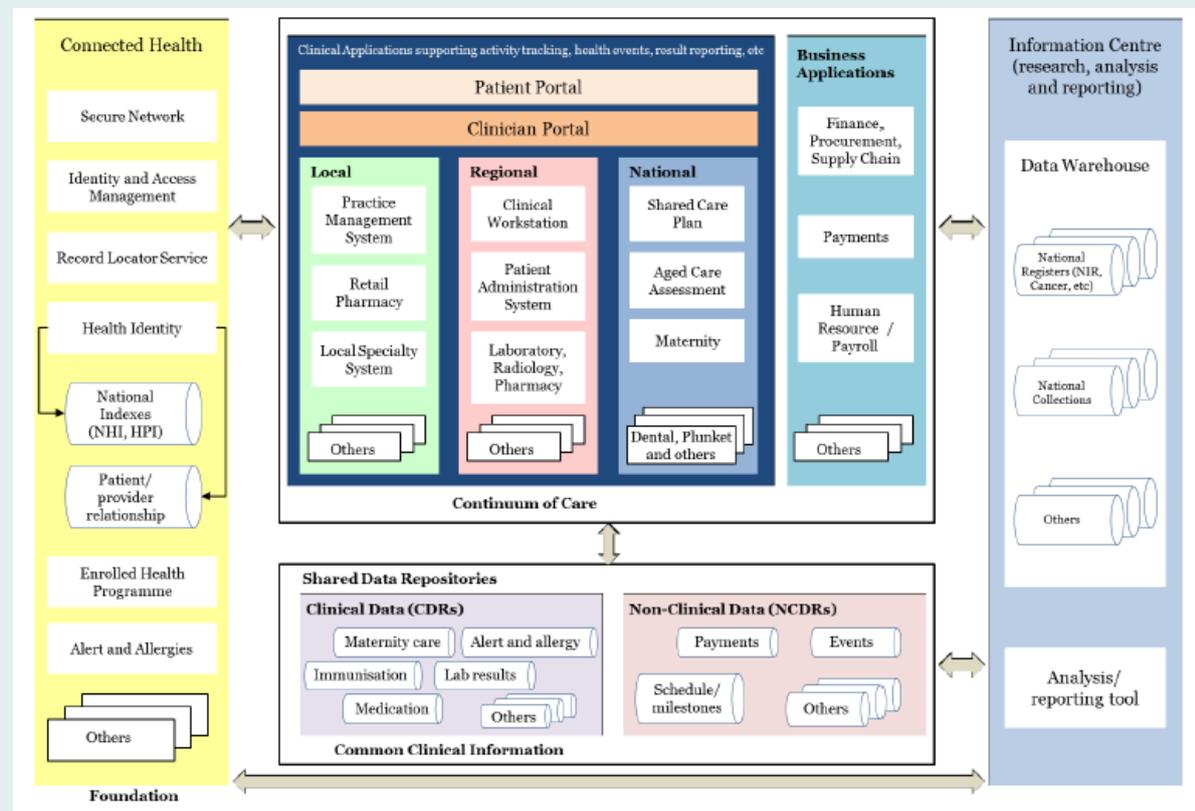
Typically, New Zealand spends approximately NZ\$300 million annually on healthcare IT. Of that, approximately NZ\$40 million is spent on primary care and the remainder is evenly split between central systems (i.e., national systems, including claims and provider payment systems and patient registries) and the DHBs, which operate the vast majority of hospitals (except a small number of private hospitals performing elective surgeries).

New Zealand is currently spending NZ\$100 million overhauling its national payment systems, which oversee payment of more than NZ\$5 billion annually to healthcare providers. A typical general practice with three full-time GPs will spend NZ\$25,000 per year on IT, including rental of practice management software, general purpose software, hardware, communications services, and technical support and maintenance.

Further investment is made by the IPAs and PHOs to provide regional support systems—this amount is estimated at NZ\$20 million, which comes directly from the practices’ operating budgets.

## 16.6 Current eHealth System in New Zealand

Figure 47. Health sector information model



Source: National eHealth Board

The sector architect group has developed [the HealthBase Enterprise Architecture Framework](#), the national IT architecture framework for healthcare. It is based on the industry “best practice” TOGAF methodology and was specifically created for the New Zealand health sector. The framework is freely available to New Zealand public health sector organizations. It is already in use across a number of DHBs.

As part of the update of the National Health IT Plan in 2013, an information model (see figure 46) was introduced. The model should guide eHealth development by summarizing the ‘end-state architecture’. The model shows how national, regional and local systems will link together to allow the sharing of relevant clinical and business information. The implementation of all major health information systems will need to adhere to the sector architecture to ensure compatibility and interoperability with other systems. The information domains are:

- **Connected Health** (yellow section) defines the common set of national functions that will support the information infrastructure. Some components have already been developed, such as the secure private health network and replacement of the NHI.
- **Transactional Applications** describes local, regional and national systems in the sector that support providers in their day-to-day clinical and business activities. These systems must integrate with shared data repositories, and with clinical and patient portals, and use the Connected Health functions.

- **Shared Data Repositories** (light green and purple sections) represent regional and national aggregations of detailed transactional data, both clinical and non-clinical. They act as a repository of information that can be used for multiple purposes, such as national collections reporting, or reference at point of care.
- **Information Centre** (turquoise section) encompasses data sets that store health event histories accumulated over time from many health agencies. The resulting data warehouse acts as a rich store of knowledge about healthcare usage, which is used for research, analysis and funding allocation.

### 16.6.1 Infrastructure

A vision and a set of principals have been developed for [national infrastructure platform services](#). [Connected Health Network Connectivity Standards have been published](#).

Health information will be transferred safely and in trusted ways by the [Connected Health](#) 'network of networks', a standards-based, commercial model for the delivery of universal connectivity across the New Zealand health sector. The Connected Health Network is delivered by multiple telecommunication service providers on a competitive basis, using industry standard, commodity capability. Only registered vendors, compliant with the Connected Health standard, can provide this service. The foundation components include:

- A common connectivity framework
- [Network connectivity standards](#) (approved by HISO)
- Core network components:
  - Three managed points of interconnection
  - A uniform addressing scheme
  - An [accreditation and certification process](#) for suppliers (telecommunication service providers)
  - Governance and management oversight

The New Zealand health sector has one of the highest levels of clinical messaging in the world. Clinical messaging has a wide range of uses, predominantly exchange of pathology and radiology reports, specialist letters, discharge summaries and information transfer to and from a range of databases.

### 16.6.2 Infostructure

[The Health Information Standards Organization \(HISO\)](#) is the expert advisory group for standards to the National Health IT Board. HISO supports and promotes the development and use of fit-for-purpose health information standards to improve the New Zealand health system, provide advice on the development of health information standards that support the National Health IT Plan, and reflect IT Health Board priorities. This includes identifying relevant international standards and advises on their adoption, scope the development of new national standards, ensure that standards are developed in an open and consistent way and participate in the standards development lifecycle by reviewing draft specifications and considering public comment submissions.

- HISO has endorsed the following standards for use across the New Zealand health sector.
- ISO/IEC 11179, Information Technology - Metadata registries
- Primary Healthcare Practice Management Systems (PHCPMS)

- Health Level 7 (HL7)
- ICD-10-AM and ICD-O
- GS1 standards
- Medicine Reconciliation and Medication Charting
- SNOMED CT (fully licensed for the New Zealand health system, the government has introduced the use of SNOMED CT as a means to have a single reference coding system in place for the country).

### 16.6.3 Privacy, Information Security, Access Control

The combination of national, regional and local systems implemented with a high degree of interoperability increases the capability of the sector, but also increases its reliance on systems and technology. The National Health IT Plan acknowledges that maintaining trust in the overall health system requires the sector to continuously improve the reliability and security of health information.

The health information privacy code from 1992 limits the reuse of personally identifiable data and mandates obtaining individuals' agreement (whether implied or explicit) for retrieving and sharing personally identifiable health information. The code is widely known throughout the sector. As a consequence there is a high level of awareness of the importance of individuals' privacy. The code has played a significant role in shaping the development of New Zealand's health information landscape. A privacy commissioner acts as a complaints authority to enforce the code.

[The Health Information Governance Expert Advisory Group \(HIGEAG\)](#) is set up to develop a health information governance framework for the sector, to provide a set of policies and guidelines on how health information can be safely shared.

The [NHITB-convened Consumer Panel](#) has developed a statement on 'Protecting personal health information – consumer expectations'. This sets out the principles for protecting privacy, and designates a framework of national requirements to strengthen confidence and trust in the use of personal health information.

Every person who uses health and disability services in New Zealand has a unique National Health Index number (NHI) as a way of identifying them. The National Health Index helps health professionals ensure the right information is available about the right person at the right time.

The Ministry of Health has undertaken a major upgrade of New Zealand's health identity systems. Through [the Health Identity Program](#), the 20-year-old technology supporting the two main health identity databases – the National Health Index (NHI) and the Health Practitioner Index (HPI) – has been replaced with a single integrated system. Health organizations access and update the National Health Index online. The solution will support role-based access, respect authorized access rights and provide an audit trail of activity.

#### 16.6.4 Shared eHealth Components and Services

**Electronic Messages** New Zealand is using the private organization [HealthLink](#) as a system integrator, providing services like electronic messaging, online services, and technical support.<sup>136</sup> Electronic messages includes clinical and administrative information, radiology and diagnostic test results, eReferrals, eDischarge summaries, EMR visit reports, specialist reports, communication with immunization databases and other national registries, and reporting on quality indicators. New Zealand was the first country in the world to use HL7-based messaging for delivery of pathology and radiology information to general practices and for referrals and discharge summaries on a widespread basis.

**Shared platform** Hospitals within one region should agree on and operate within a shared service platform. The content of this platform is decided nationally and contains:

**Patient Administrative System (PAS):** handles the administrative details surrounding the patient's meeting with the healthcare service. The system supports administrative routines in order to secure that hospital resources are used to ensure efficient service provision with regard to for example staffing, rooms, beds and equipment. Key functionality is typically hospitalization routines, surgery waiting lists, medication use, and billing. PAS is integrated with national patient registry. PAS functions both as a receiver of patient information and as a sender, for example for enterprise-based discharge notes. Shared PAS will be consolidated as outdated systems are replaced.

**Clinical work station (CWS):** a web based system, which links multiple clinical applications and data sources in order to give healthcare personnel secure access to health information and functionalities. CWS should give users an easy and secure and coherent user interface that supports work processes. Orion Concerto CWS is installed in all regions. The aim is that configurations, interface, and access policies will be national. An important source for information in CWS is a clinical data repository (CDR), typically tightly integrated with CWS.

**Regional clinical data repository (CDR):** contains identifiable clinical information such as medication usage, test results, radiology reports, care plans, patient letters and discharge notes. Information is stored in real-time or during continuous intervals by means of technical standards. Authorized users can access data directly through a CWS or a web portal. Data can transfer to other systems by request. Other systems, including the ones the patient use, will have access by means of defined standards. The aim is that all regions share a CDR, while the technology used to gather clinical data at the point of care can vary between the regions as long as this is done in a standardized manner.

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<sup>136</sup> A health system integrator (HSI) is a specialized information technology company with expertise in integrating and supporting messaging, online communications, and security systems. HealthLink provides electronic communications and data security services to healthcare organizations across New Zealand, Australia, and the Pacific. With 70 staff members, the organization provides commercial health information exchange services enabling the delivery of more than 60 million items of clinical information annually. It also provides technical support for a wide range of New Zealand government-owned and operated data facilities and health management programs.

**Electronic Shared Care Record View (eSCRV)** The eSCRV provides a view of a patient's relevant health information from a single log-on, including information from hospitals, GPs, community nurses and pharmacies. Clinicians will have access to an integrated overview of the EHR across all regional CDRs through their CWS, which leads to faster diagnoses and treatment, and shorter waiting times.

**GP2GP file transfer** GP2GP allows different practice management systems to 'talk' to each other, meaning patient records can be electronically transferred immediately and securely at the touch of a button. The system is now being used in more than 80 percent of practices, with more than 20,000 patient files transferred each month.

**ePrescribing and administration (ePA)** Electronic communication of prescriptions has lagged other forms of health sector communication, but electronic prescribing trials involving hospitals, general practices, and pharmacies are now under way. All DHBs are expected to have ePA in place by 2016.

**Electronic medicines reconciliation (eMR)** Three DHBs have implemented eMR, and all DHBs are expected to have the system in place by 2016. A national contract has been signed for integrating eMR with ePA. The system helps health professionals create the most accurate and up-to-date list available of a patient's medicines on presentation. eMR captures a patient's medication history from sources such as eReferrals so medicines can be reconciled electronically on admission to hospital, on subsequent hand-over points, and on discharge from hospital.

**New Zealand Formulary** The New Zealand Formulary went live in July 2012. The Formulary is a point-of-care reference which provides clinical information about medicines, their use, contra-indications and side-effects. It supports the day-to-day needs of those prescribing, dispensing and administering medicines. The Formulary is based on the New Zealand Universal List of Medicines combines standardized medicine descriptions from the New Zealand Medicines Terminology with information from Medsafe and the PHARMAC Pharmaceutical Schedule to create a one-stop shop for medicines information. New Zealand Formulary is continuously updated, accessible online and on portable devices, and in time will be fully integrated with the e-health environment, including prescribing and dispensing software.

**National Shared Care Program (Long-Term Conditions)** A [shared care planning tool](#) is under development (some regions have implemented) for clinicians who are managing patients with complex, long-term conditions such as diabetes and heart failure. The plan is a simple, shared record which is structured and exhaustive. The plan should support cross-disciplinary coordination, and is developed by patients, next of kin, and healthcare personnel. The plan defines shared agreements about problems, goals, actions, timelines and responsibilities for all parties involved. The aim is improved communication and collaboration, and optimal patient involvement in order to reduce complications, increase productivity and quality of life. It involves patients setting goals for the management of their health conditions and sharing that information with the clinicians involved in their care. The shared care system has also been adapted to handle medication management plans for patients with long-term conditions.

**Maternity Clinical Information System** A new way of collecting, sharing and viewing maternity and neonatal data is being developed that will allow women and their healthcare providers to have electronic access to their maternity information. The new system will bring together relevant information collected in the community and hospital about a woman's pregnancy. A national

contract has been signed for the first stage of implementing the new system, which includes portal access to a shared maternity record view. Implementation began in 2014.

**Comprehensive clinical assessment for aged care (InterRAI)** InterRAI provides an electronic clinical assessment of the care required for an older person to be shared among healthcare providers to make sure everyone has access to accurate, up-to-date information. The system has been implemented in all DHBs and is now being rolled out to aged residential care homes, with completion expected by July 2015.

### 16.6.5 EHR Landscape

There are approximately 20 vendors whose products range from physician office systems to specialized systems for physiotherapists, laboratories, and radiology service providers. There are five vendors providing physician office systems for primary care. Of these, one has a dominant market share of 80 %.

The movement in the early 1990s toward a primary care–led health system was accompanied by a similar movement toward EMRs. In 1998, the government gave GPs a one-time grant of approximately NZ\$5,000 (US\$3,600) to purchase computers. At the same time, it notified GPs that it would make electronic claims compulsory within two years. A further catalyst for change was the government’s requirement to submit patient disease information to registers and to file fee-for-service claims electronically in order to receive subsidies, combined with financial incentives for primary care. By 2000, more than 98 % of GPs used a computerized billing and appointment system and more than 50 % used a computer system for capturing clinical information during patient consultations. In 2010, 100 % of GPs had a computerized system and 92 % had advanced clinical functionality. Primary health organizations and independent practitioner associations have played a key role driving digitization by dedicating IT staff and clinical staff with IT training to work with EHR vendors.

### 16.6.6 Digital Services for Citizens

The National Health IT Plan Update refers to a growing body of evidence suggests that people who feel able to make decisions about their healthcare often end up choosing lower-intervention and lower-cost options compared with the decisions often made by clinicians in traditional healthcare settings. In order to do this, patients and consumers need reliable access to their health information and to understand the various clinical options available to them. Clinicians, meanwhile, need to be confident users of eHealth solutions and support the use of patient portals by consumers.

On this background, as well as the desire to empower patients, New Zealand has a strong focus on providing digital access for patients throughout the strategy period.

Patient portals allow patients to access their health information securely online. They are sometimes referred to as ‘self-care portals’. The portals allow people to communicate electronically with their GPs, make appointments, view their records, check their lists of medicines and renew prescriptions. The NHITB is working with primary health organizations and integrated family health centers to introduce secure electronic self-care portals. Two Patient Management System vendors have developed portals, which are in use in a number of places.

### 16.6.7 Secondary Use of Data

- National patient registry since 1980s
- National cancer registry since 1948

The Ministry of Health and Disability has the overall responsibility for [health statistics](#). The official web sites and health IT Plan has no mentioning of ongoing efforts with regard to developing or using eHealth system to progress secondary use of health information.

## 17 China

### 17.1 Demographic Data and Political Tradition in China

Population (2014)	1 357 380 000
Area (km <sup>2</sup> )	9 596 961
Political tradition	Socialist single-party state
Administrative levels	State, province, county/district, township

### 17.2 Key Figures for the Chinese Healthcare System (2011)

<b>Health status</b>	
Life expectancy at birth (years)	75
<b>Expenditure on health</b>	
In percent of GDP	5.2
Per capita (USD purchasing power parity)	432
Public financing (% of total expenditure)	56 (2012)
Private financing (% of total expenditure)	34.3 (2012)
<b>Health workforce</b>	
Practicing doctors (per 1000 population)	1.5
Practicing nurses (per 1000 population)	1.7
<b>Healthcare activities</b>	
Doctor consultations (per capital per year)	5 (2012)
Hospital discharges (per 1000 population)	71
Total hospital beds (per 1000 population)	2.75
Average length of stay, all causes (days)	10.3 (2010)
<b>Access to healthcare</b>	
Coverage for healthcare (% of total population)	
Out-of-pocket medical spending (% of household consumption)	

Source: OECD 2013

### 17.3 Gathering Information on the Chinese eHealth System and Choosing Case Study

In the Chinese case we have chosen to concentrate our study on a regional development project in Shanghai rather than developing a full-fledged analysis of the Chinese national eHealth system. This has to do with the very various stages of the Chinese regions in implementation of the national *One patient - One record* program. Nonetheless, in order to understand the regional development within eHealth, it is of importance to understand the ongoing national healthcare policy reform, and the specific role of eHealth therein. Hence, in the following we shall start by describing describe the Chinese healthcare system and eHealth program, before moving on to the case study from Shanghai.

The empirical material for the chapters on the development of eHealth in China and Shanghai was gathered through:

Desktop research, May-June 2013 and January-March 2015: Official documents and web sites of governmental actors and sector organizations were explored to gather background on the Andalusian healthcare system, eHealth strategy, key actors and initiatives.

Study trip: to Shanghai and Ningbo, was organized by the Norwegian Ministry of Health and Care Services in November 2013. The event was organized around the following program:

PROGRAM FOR THE NORWEGIAN STUDY TRIP TO CHINA NOVEMBER 2013		
Shanghai, Changning	Sunday	Norwegian Consulate of Shanghai, China
	Monday	City Health Bureau, Information center
	Tuesday	Maternity and Infant Hospital Community healthcare center
Ningbo	Thursday	City Health Bureau
		Mother and Child Hospital
		Mobile Smart City – Internet of Things Showroom
	Friday	Community Healthcare Center City Development project

On the basis of the information gathered throughout the study trip, the report was updated focusing on the Shanghai experience with realizing policies in practice. Obviously, the description is not exhaustive. The content of this report reflects the knowledge needs of the Norwegian *One patient – One record* program. When situated perspectives and viewpoints are expressed, we highlight this by referring to the source.

#### **17.4 Financing, Governing and Organizing Healthcare**

In recent years, China's GDP growth rate has on average exceeded 9 % annually. Health expenditures in China have increased just as expansively, pharmaceutical expenditures in particular (39 %), and are expected to reach USD 600 billion by 2015 - a threefold increase from 2000.<sup>137</sup>

Urbanization, environmental pollution, and wealth disparities, in combination with one of the world's fastest ageing populations has led to widespread health problems in China, of which the rapid increase of chronic care patients is a key challenge.<sup>138</sup>

From the early 1980s to the early 2000s, the financing of healthcare was gradually driven by the introduction of a market economy, which replaced a planned economy. However, facing growing

<sup>137</sup> [http://www.tillvaxtanalys.se/download/18.5f097bc113eacc3d6d513e/1369033621751/direct\\_response\\_2013\\_03.pdf](http://www.tillvaxtanalys.se/download/18.5f097bc113eacc3d6d513e/1369033621751/direct_response_2013_03.pdf)

<sup>138</sup> More than 200 million Chinese citizens suffer from high blood pressure, resulting in 2.3 million deaths per year. China has more than 90 million diabetics and nearly 150 million showing early symptoms. China is home to 350 million smokers, contributing to an estimated one million related deaths per year. Other serious health issues associated with China's rapid development include respiratory illnesses as well as growing incidences of cancer, cardiovascular disease and obesity.

disparities in access to healthcare and escalating costs throughout the 1980s and 1990s this financing model of healthcare system was seen as unsuccessful.<sup>139</sup>

The strong call for more equity, combined with citizens' increased standards of living and growing expectations towards better quality of care, in 2009 the Chinese government embarked on a 125 billion dollar healthcare reform. Under the label **Healthy China 2020** the government aims to ensure that the State plays a critical role in guaranteeing universal coverage of comprehensive universal basic healthcare for all its citizens by 2020.<sup>140 141</sup> The reform is operationalized in the **12th Five Year Plan for National Economic and Social Development (2011-2015)** which emphasizes:

- **Broader basic healthcare coverage:** supporting the government's goal to provide basic medical coverage for over 90 % of the population
- **Develop primary healthcare infrastructure:** build community healthcare centers and invest in county hospitals in rural areas and township medical stations
- **National Health Action Plan:** build public awareness of disease prevention, particularly for high-risk groups in regard to diabetes, cancer, hypertension, and infectious diseases;
- **Improve healthcare administration:** improving overall hospital management, including upgrading hospital information systems, and hospital personnel training
- **Healthcare standards:** establish national healthcare indicators that will serve as benchmarks for national health goals including indicators for healthcare, health resources, and health investments
- **Healthcare IT:** investing heavily in healthcare IT, including systems integration and digital and remote provision of services to secure healthcare delivery efficiencies.

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<sup>139</sup> <http://www.biomedcentral.com/1471-2458/12/S1/S9>

<sup>140</sup> <http://www.who.int/bulletin/volumes/88/1/10-010110/en/>

<sup>141</sup> The governance of the Chinese healthcare system is described as highly fragmented. Healthcare is under the leadership of National Health and Family Planning Commission, but healthcare governance has been decentralized among Bureaus of Health in 31 provinces/autonomous regions. Overall healthcare system reform is governed by the State Council Healthcare Reform Leadership Committee while other ministries carry out healthcare system development and reform using a multi-sector approach and issuing important healthcare reform guidelines and documents.

**Figure 48. Chinese Healthcare system**

<b>Urban employee basic medical insurance (UEBMI)</b>	Mandatory insurance that provides all urban employees with medical insurance funded through a combination of social pooling and individual medical savings (payroll tax, 6 % employers and 2 % employees).
<b>Urban resident basic medical insurance (URBMI)</b>	Covers urban residents that are not covered by UEBMI, including middle and primary school students, children, adolescents, the elderly and other groups requiring social aid (the poor and disabled). Contributions are collected by household with some subsidies coming from the government. Coverage includes only hospitalization and catastrophic illness.
<b>Rural cooperative medical system (RCMS)</b>	Financing through a combination of individual contributions, financial support from collective enterprises and government subsidies. Reimbursement is divided into three formats - catastrophic illness insurance (inpatient) + medical saving accounts (outpatient), catastrophic illness insurance (inpatient) + ambulatory fund (outpatient) and catastrophic illness insurance only.

Source: Swedish Agency for Growth Policy Analysis (2013)

China's Social Insurance Law was formally enacted in 2011 and includes three basic medical insurance schemes (see table 1), covering 95 % of the population. Healthcare is financed by government input (30.4 %), private insurance (34.7 %) and individual out-of-pocket payments (34.9 %). Individual medical insurance is paid through income tax, and divided into an individual saving account and a social pooling fund. Taxation levels vary, with Shanghai at the top with 10 % for employers and 2 % for employees. The individual saving account is used to pay for minor outpatient expenses and for inpatient diseases. Medical expenses are paid in advance by patients and later reimbursed by insurance, which is a great financial burden for many Chinese. In general, a high medical expense compared with citizens' average income is a widespread problem.

Despite comprehensive coverage being offered through the three basic medical insurance schemes (UEMI, URMI, RCMS), many problems remain. There are significant healthcare disparities between urban and rural areas, which again are closely linked to the regional, socioeconomic differences. Most third tier hospitals are located in central districts, such as Beijing, Shanghai and Tianjin possessing world-class capabilities, while other regions lack even basic care for much of its population. Inequalities also exist within the more developed districts. Since residents in for example Shanghai need a fixed salary, a Chinese passport and a permanent resident card to be insured, over 150 million rural residents that have migrated to urban areas are unable to transfer their coverage, which means that any medical services provided outside the individual's original locality will not be reimbursed in the location of treatment.

**Figure 49. Organization of healthcare in China**

<b>Hospitals</b>	21.979 Total number of hospitals (61.6 % public)
	14.328 General hospitals
	2.831 Traditional Chinese Medicine hospitals
	4.283 Comprehensive hospitals
<b>Primary healthcare facilities</b>	918.003 Total number of Primary care facilities
	32.860 Urban community health centers
	37.295 Rural township health centers
	184.287 Outpatient clinics
	662.894 Village health posts
	11.926 Total number

<b>Public health institutions</b>	3.484 Centers for Disease Control 1.294 Hospitals for special treatment and disease prevention 3.036 maternal and child healthcare centers 3.022 health supervision institutions
<b>Traditional Chinese Medicine</b>	Exists side by side western medicine in hospitals and community healthcare centers. Patients stand free to choose which intervention to use <sup>142</sup>

*Source: Swedish Agency for Growth Policy Analysis (2013)*

The concept of primary healthcare is relatively new in China, introduced in the 1980s. According to the “Six in One” principle a community health center shall offer services within the areas of prevention, health protection, medical treatment, rehabilitation, health education and consultant for family birth-control.

In most European countries, a primary care institution is usually the first point of contact for patients, acting as a gatekeeper to the specialist service. In China, patients have traditionally lacked confidence in the diagnostic skills and quality of treatment in smaller hospitals. Attracted by stronger competence and more human resources, patients have therefore gone directly to a hospital, even for slight discomfort as cold. As a result, most city-level hospitals are overloaded with patients. The situation is costly and threatens to reduce quality of care because as hospital doctors are under pressured to serve more patients in less time.

The government wants to re-organize the whole medical procedure and establish the community health centers as the first line of service to reduce pressure on hospitals and cut costs. Consequently, work is ongoing to improve the overall access to and quality of primary healthcare services. In addition, there are plans to establish a family doctor model at the community level.

To raise the quality of care and strengthen the position of the community health centers the government is building thousands of new healthcare provision facilities, upgrades the medical devices, and develop the country’s healthcare IT market, particularly in areas such as establishing and managing EHR and improving healthcare IT application.<sup>143</sup>

In the following, we shall first describe the national initiatives framing the development of Chinese eHealth. Thereafter, we will explore the realization of the national visions, focusing on the development of eHealth in Shanghai, a regional frontrunner in the development of Chinese eHealth.

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<sup>142</sup> For more information about the TCM industry and its regulation, see: <http://www.catcm.org.cn/english/index.asp>

<sup>143</sup> *Notice by General Offices of NDRC and MIIT on Improving Electronic Information Technology Industry and Technology Transformation (2009)*: The notice emphasizes healthcare IT will be one of China’s investment focuses in upcoming years.

## 17.5 eHealth Strategy in China

The SARS epidemic of 2003 revealed China's shortages in dealing with emergencies through using information tools, and exposed the lag in the general health information system. Key challenges that have hindered development of Chinese eHealth were identified as:<sup>144</sup>

- Fragmented system: Each medical organization operates individually.
- Information is not shared and exchanged.
- Lack unified national standards for some medical operations and information system.
- Lack overall plan for informatization construction.
- Horizontal construction of information system complicated the sharing of information among medical institutions.
- Lack of talents and investment

The combined result of these shortcomings was a highly decentralized health information system without connection between medical records, statistics, equipment data, medical data and financial data within and between hospitals and community health centers.

Realizing the importance of integrating an effective IT infrastructure, in 2003 the Chinese government began work on a coherent national eHealth system. "The national health information technology development guideline" was published and is the background for the recent efforts towards the national *One citizen – One record* initiative.

Following the governmental ambition to create a national eHealth system, the time ahead until 2020 is envisioned as a key period for the eHealth industry in China.<sup>145</sup> The government wishes to consolidate the diverse IT resources – such as platforms, centralized servers and customized PC networks – used across China's various regions. The focus is on the implementation of information systems in hospitals, a national information network and public health network with information about diseases, epidemics, medicine and treatment. The strategy has also included the development and implementation of telemedicine, health records, web pages and standardization. Expected effects goals are:

- Improved healthcare process by encouraging more coordination of care and reducing pressure on hospitals.
- Improve user satisfaction for citizens by reducing waiting time and offering seamless care
- Develop data for quality indicators and development of a more result-based system, which enable stronger governance through monitoring of enterprise and personnel performance and public health tendencies

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<sup>144</sup> <http://www.etn-uk.com/Portals/0/Members/Ashley.evans/E-health%20report-4%20Market%20report.pdf>

<sup>145</sup> According to estimates, China allocated 1.2-1.8 % of the total USD 125 billion toward healthcare IT, or approximately USD 1.45 billion to 2.6 billion incremental spending for 2009-2011. China's hospitals account for the vast majority of healthcare IT spending and represent 73 % of the total. Capital spending is a highly decentralized process with each hospital making its own purchasing decisions.

In the wake of the political attention to health IT development, the Ministry of Health has issued a pilot action plan for the nationwide EHR system. 22 pilot alliances are formed between regional hospitals in major cities with the goal of integrating regional healthcare resources. The projects include EHR systems for residents, an exchange of EMRs between hospitals and community health centers, medical information inquiries, billing of medical expenses, and dynamic monitoring of health status.

Having analyzed domestic and international trends, at the end of 2010 the Ministry of Health<sup>146</sup> published a "people-centric" health information technology plan, the so-called 3521-2 program<sup>147</sup>, which aims to establish a national EHR system and health archives that can cover the whole life cycle for each citizen. At the same time, the construction of three-level health information management platforms and health information standard system is speeded up all over the country. By 2015, the aim is that China will have built the basic framework of the national health information systems. The rate of residents who will have a health card and standard EHR will reach 30 %. In addition, all class 3 hospitals in China must by then have a complete EMR for each patient, and one-third of the class 2 hospitals need to have partial electronic archives for patients.

### ***17.6 The 3-5-2-1 Project***

The basic idea of the 3521-2 project is to solve the problems of where to collect, where to save and who to access the data.

The aim is to set up a **3-level health information management platform** which is nationwide, provincial-wide and prefectural-wide. The nationwide platform will support cross-province medical and health information sharing, business collaboration, and improve the ability to deal with public health emergencies; the provincial-wide platform is created to support intercity medical and health information sharing and business collaboration; last but not least is the prefectural-wide platform which is aimed at building up a regional health information management center. Establishing an integrated information platform within this area will enable the information exchange between different medical institutions and relevant departments.

The government's ambition is to enhance the application of **5 service area systems**:

- Public healthcare system
- Healthcare system
- Medication control system
- New rural cooperative medical system
- Comprehensive management system

The program builds on 2 sources to data, one for EMRs and one for EHRs. An EMR is defined as a local medical record used to document consultations. An EHR is the data standard for formatting

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<sup>146</sup> Now called National Health and Family Planning Commission.

<sup>147</sup> The plan is financed by central government with special funds from the central financial transfer payment.

“cradle-to-grave” health information. All authorized users should have access, which realizes the information sharing function among different healthcare organizations. EHR systems should include data of disease prevention, health protection and health promotion and it is set up to govern the transmission and interoperability of medical data between healthcare facilities and doctors, pharmacies and the wider healthcare establishments. The EHR system is also closely linked with the need to develop Regional Health Information Networks (RHIN).

The objective is to reinforce the construction of information standards and an information security system. There are 2 main tasks for the information security system. First, to improve the information monitoring system, establish an emergency plan for information safety, and complete the reporting system. Secondly, to strengthen the construction of the disaster preparedness system and improve the ability to recover information infrastructures and important information systems.

The aim is to establish **1 national information network** (three-tier), by linking the three platform levels and other entities/authorities in one, “physical” national health net.

The construction of information standards will be conducted with reference to international standards as a reference, but modified in order to fit the Chinese model. The Ministry of Health has developed national standards on technical aspects + minimum clinical dataset (EHR architecture and data + EHR functionality). The national EHR standard further states that Health IT systems should support decision support tools in areas where clinical pathways have been described and standardized. There is a national program for developing standard clinical pathways and control with chronic disease, but these needs to be adapted locally, and have with room for local modifications. The guidelines are developed based on international research. The different enterprises hold the responsibility for integrating these in the local EHR system (adapting and updating).

In general, the national standards are described as broad, leaving considerable room for regional flexibility with regard to the actual EHR/RHIN solution in practice. The different cities involved in piloting the national EHR system are, thus, working with different solutions and implementation processes. Acknowledging these differences, and the fact that Shanghai has one of the most robust eHealth systems in China, in the following, we will go in-depth on the eHealth developments in Shanghai as the leading city when it comes to implementation of national e-health strategy. In particular, we take a closer look at the status of eHealth in the district of Changning among the leading districts in Shanghai.

## 18 Shanghai

### *18.1 Demography, Health Status and Healthcare System*

Officially, Shanghai has 23 million inhabitants. Due to strict implementation of the birth-control policy and improvement of medical conditions, Shanghai is the fastest ageing city in China. More than 20 % of the Shanghai's citizens are above 60 years old. The figure is increasing, and represents double the proportion of the national average. Shanghai also has the highest prevalence of chronic diseases, with over 4.5 million people suffering from chronic health problems. To serve the healthcare needs of a large and ageing population, considerable effort is put in to improving and deepening the ongoing national healthcare system reform.

The healthcare system in Shanghai is headed by the [Municipal Health Bureau](#) and its sub agencies. The bureau represents an administrative department of the Chinese Ministry of Health and its main duties are to implement the national policies, carry out plans for developing Shanghai health services, and supervise public health. The sub agencies of SMHB include 7960 health institutions, consisting of licensed medical hospitals and clinics providing healthcare services, Diseases Control Centers at all levels and medical supervision and research institutions. The cities health Information centers are responsible for the development of Regional Health Information Networks (RHIN).

The public healthcare system in Shanghai is organized according to a three tier system:

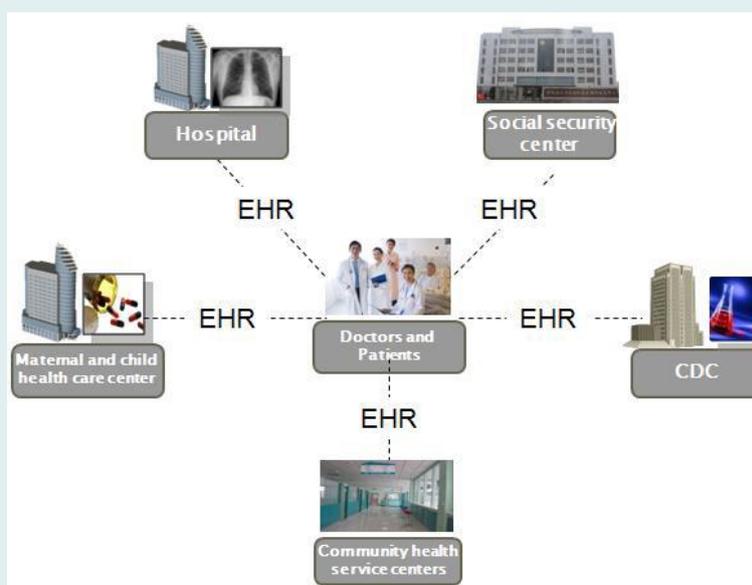
1. **Community Health Service Centers** (within a community). Mostly situated near the densely inhabited districts, offering neighboring residents general medical treatment, health consultant, maternal and child care. There are three basic avenues for healthcare within the system: standard outpatient visits, at-home visits, and self-service clinics.
2. **District hospitals** (in between several communities). Provides inpatient and outpatient services (ca. 300-400 beds), focus on the diagnostic of diseases within their districts and perform less complicated surgery, such as fractures or appendix operation.
3. **Comprehensive hospitals and specialized hospitals** (in between several cities/districts). Offering high-quality medical treatment (500 + beds) and research through linkage to major universities. Hospitals have national areas of expertise.

### *18.2 Developing a Regional eHealth System in Shanghai*

In response to the government's call for wider utilization of IT in healthcare, and awaiting the specification of national standards, some provincial authorities are moving ahead with regional implementations. Shanghai, together with Beijing, is taking the lead. Building on the national "3521-2 model", the city has developed a RHIN pilot and built the basic infrastructure for a unified healthcare IT platform. The information in the platform is currently only available for users in Shanghai. The ambition is to make information available across the nation.

The Shanghai RHIN now covers more than 600 healthcare organizations and has set up 4 database centers: the main data is from public hospitals and supplemented by institutions such as the Municipal Health Bureau, the Municipal Center for Disease Control and Health Control Bureau.

Figure 50. Regional health information platform based on health records



Source: Shanghai Health District Changning

The actual implementation of the Shanghai RHIN varies across the different districts of the city. The following description is based on input from the study trip to Changning district.

The district authorities spent seven years to develop the system. The development of the platform has been ca 40 million NOK, with an annual 10 million extra for maintenance. In total, including local implementation, the costs of the system has been ca 80 million.

The District Health Bureau describes the solution as resource demanding to operate, demanding much work on quality control of the databases.

The Shanghai RHIN project originally started with a focus on management and quality control. The first three years after installation, healthcare personnel were resistant to use the system. This stemmed both from skepticism among healthcare personnel, doctors in particular, regarding the monitoring aspect of the system, and from the experience that the system was too difficult to learn and use. This led the District Health Bureau in Changning to work on the usability of the system, which increased acceptance. Once healthcare personnel started using the platform, they also started seeing its potential with regard to continuity of care and a more informed and active patient role. As a result, the sentiment changed. Today, it is healthcare personnel that contact the regional Health Bureau with requests for updates and more functionality.

### 18.2.1 Infrastructure

The concept is based on a shared portal that integrates, and gives access to information in local systems. The portal is online, while the different modules are local installations.

Through the RHIN, existing and new systems are maintained, developed and integrated on the same platform. It is the responsibility of the enterprises to maintain their respective integrations with the RHIN (project, implementation, budget, procurement). The district health bureau is responsible for integration mapping if i.e. coding systems are different between healthcare organizations.

Some systems, like the birth registers and the vaccination program, already had full vertical integration (local-national), others were local EMRs. Information (notes, pictures, test results, etc.) is documented locally and transferred to district level database, and further aggregated upwards through the levels of the RHIN – district>city>province.

The database for Changning is located at the Health Information center for the District Health Bureau. Data is being harvested every night and then transferred further to central level and made available for other healthcare personnel and patients through log in on the portal.

In general, the RHIN/EHR systems are built on existing software - standard Microsoft windows components and menus - which make them user-friendly, given that the user is familiar with the Microsoft office package. The strategy is to avoid excessive training by building on existing IT competence. Eight vendors and one platform provider have been involved in the development of the system.

### **18.2.2 Infostructure**

Within the broader national 3521-2 framework, the Health bureau has developed regional standards for information security, data storage and HIS functionality.

The EHR system is based on structured (international) coding.

The EMR is standardized. When health personnel look up information from another enterprise, this is shown through an interface in the shared portal. The system contains filters, in order to make available only the most relevant information. The data in an EMR is not automatically integrated into the EMR of other personnel groups. If a doctor wants to use information from a hospital record in his/her EMR system, this has to be transferred manually.

### **18.2.3 Privacy, Information Security, Access Control**

It is mandatory for (public) healthcare personnel to use the RHIN and for the patients to have their information documented in the system. This is because reimbursement is based on information from the EHR system. When patients visit a community health center they sign a contract with the doctor, saying that the patient will use the center as the first line of service. The contract states that the patient consents to his/her medical record being linked to the RHIN. Healthcare personnel can only see a patient's information on the day that the patient consults the doctor, and only if there is a written contract between patient and doctor.

Use of the platform is regulated by a role-based system for access control. Healthcare personnel can either log on to the system by swiping their identity card on a card reader at their work station, or they use a code (deriving from a national healthcare personnel register) and an eID to log on online through their smart phone, pc, pad. All patients who hold a medical insurance will also receive an identity card issued by the healthcare enterprise they receive service. The social security number is the patient identification and is linked to the card. If patients wish to log on online, they use their eID and a pin code, and receive a password through SMS.

Figure 51. Picture from study trip: Terminals for Patients visiting Healthcare Facility



When patients visit a community health center or a hospital, they swipe their card on terminals standing in the foyer and/or at card readers next to the doctor's work station. This allows the data that is generated throughout the visit to be automatically harvested and stored and attributes all actions taken by the provider directly to that patient.

The card is used for health service registration, treatment and payment. Health data is not stored on the card. It will also record all personal medical information. Information about residents will also be used by community hospitals for chronic disease management and control.

The system produces an audit log, which is only accessible for the enterprise managers, not healthcare personnel and patients.

To protect privacy, particularly sensitive information such as data concerning HIV/AIDS and tuberculosis, is recorded in special, isolated systems that is not integrated with the shared platform.

#### 18.2.4 Shared eHealth Components and Services

Changning has completed the hospital and community health information systems integration and realized a two-way switch between the hospital and community health services through electronic health records information platform.

The entire healthcare information of patients' is available in and between the district's healthcare enterprises. The aim is to support the continuity of care, and for healthcare personnel to be able to make a more accurate diagnosis and provide better treatment.

Through the portal, users have access to different platforms with different interfaces for different user groups: *Governance, Patient, Hospital, Community health center* (mainly for doctors), *Traditional Chinese medicine*.

With an identity card or online log in, healthcare personnel have access to the platform and are able to work real-time both in the patients' EHR and EMR and make prescriptions.

Children that go to school are required to follow a vaccination program. Through the platform schools can enter the vaccination registry, give name of pupil + social security number and check vaccination data for their pupils.

There is no ePrescription solution. Hospitals sell medicines and it is therefore not common that the patient get his/her medication from elsewhere, hence not considered useful with a city wide ePrescription solution.

### **18.2.5 EHR Landscape**

#### **An Example from the Community Health Centers**

In accordance with national healthcare policy, Shanghai has since 2007 issued reforms aimed at redistributing medical resources and improving the standard of small-sized hospitals and community healthcare centers in order to reduce pressure on hospitals and establish community health centers as the 1<sup>st</sup> line of service. The shift from local EMR systems to the implementation of an EHR centric RHIN plays a key role in this.

The Changning district has completed the digitization process, and is in the process of sharing information across levels and building services on top of the shared digital platform. Today ca. 2.300 doctors are sharing information across 16 hospitals.

Regional collaborative alliances are built between community health centers and secondary and tertiary hospitals. Community health centers are established as the first point of contact. If further care is needed, the community doctor can refer the patient to a secondary or tertiary hospital for necessary treatment. During the recovery period, the patient can return to the community health center for rehabilitation. Hospital alliances are to strengthen the vertical integration of service providers and support seamless medical care and increased efficiency in the healthcare system.

As it is not mandatory for patients to use the community health centers, an incentive structure has been developed. Primary healthcare doctors are assigned responsibility for communities. On the first visit to a community health centers, the patient is presented with a contract which declares that the patient will use the community health centers as the 1<sup>st</sup> line of service, and not go directly to a hospital. In return, the patient saves the registration fee and cost of consultations. The community doctor is then responsible for the entire health management of this person, not only medical assistance.

This focus on health, in contrast to the more narrow medical treatment, is also reflected in the doctor's contract with the community health centers, in which half of the work is dedicated to medical work, and the other half to public health work. In particular, the focus is on chronic care management. As the costs of chronic care in community health centers are usually much lower than in the hospitals, community health centers have gotten extended responsibilities and efforts are made to improve the quality of chronic disease management in the community health centers. Important here is the development of national clinical pathways, on diabetes that instructs the doctors on how to identify and follow up on patients who are at risk for developing the disease. The guideline is integrated in the EHR system and linked to the contract signed between community health center doctor and patient. During the first control at the community health center, all patients above 35 go through a screening process where blood pressure and blood sugar level is measured and a treatment plan is designed on demand. The consultation is registered in the EHR and serves as data for management monitoring public health and health personnel performance in accordance to national standards. In the register, patient data is not anonymous to ensure easy retrieval and follow-up on individual patients, but patient consent forms are required to use the information.

To further strengthen the quality of care and improve level of trust in community health centers a comprehensive nursing care system has been established to assure that patients dismissed from hospital receives appropriate follow up from his/her local community health center. The hospital sends a message to the EHR system, upon which the responsible nurse will conduct home visits to assess the patient's condition and work out a comprehensive care plan. The patient and his/her family will be given guidance for their recovery at home. If needed, community health center doctors will also do home visits. This multi-location provision of care, was a key driver for the development a multi-device solution, allowing healthcare personnel – and patients – to access the RHIN from PC, pad, or smart phone according to which device is available at the point of care.

The changing role of the community health centers, as collaborating partners of hospitals, and their increased responsibilities for public health work, including reporting to the national level, was an important driver for further development of the RHIN. The platform allows the sharing of information in and between the different health providers.

Knowledge transfer among different levels of care and competence building among staff in community health centers is a key driver for the development of the system. Accessing the system, healthcare personnel throughout the entire healthcare system share information on specific patients. This is seen to support the continuity of care and gives patients a seamless service experience.

**Figure 52. Picture from study trip: Community health centers offer x-ray and ultrasound services, also in collaboration with specialists at hospital through use of telemedicine.**



What is more, sharing information also increases the knowledge and competence among staff at the community health centers. When a hospital treats a patient, a code and a description of diagnosis

are registered and shown in the EMR system of the community health center. This gives the community health center doctor access to the assessments and interventions of the specialists, which becomes a source of learning. Telemedicine is also utilized for the same purpose. At the community health center the patient has access to x-ray and ultrasound services. Through remote access to hospital specialists, community health center doctors can call in for live consultations to assess images in collaboration with the experts.

A main objective following the Shanghai RHIN implementation is to increase the user friendliness /patient satisfaction at the community health centers in order to recruit more patients. Hence, services offered today are electronic bookings (online or terminal), use of SMS to avoid waiting lines, information regarding personal biographies, professional specialties and waiting lists accessible online or displayed on screens in the community health center waiting area.

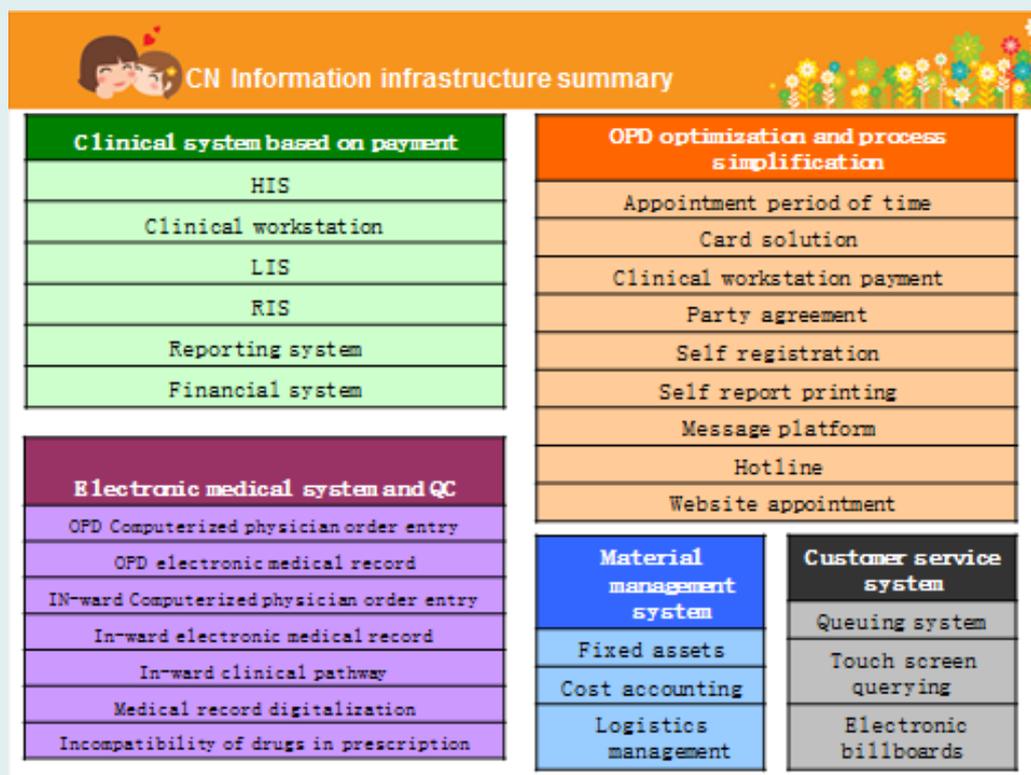
**Figure 53. Picture from study trip: Self-monitoring devices placed in community health centers.**



Following the focus on chronic care patients, the community health centers have also developed self-monitoring areas, in which the patients can enter at any time to have blood pressure and weight measured and registered in their EHR. The responsible community health center doctor will automatically be alerted if there are abnormal values, and the patient can have the results assessed.

All community health centers use the same EHR software, which makes it possible to see information of individual patients at any center within the district. Doctors can retrieve information about medication, discharge notes, chronic care plan, lab and x-ray results, and functional test scores. The system contains a calendar and work schedule planner and a system for administrating appointments. The system reminds the doctors if a patient already had a test, to avoid unnecessary interventions. This is seen as a major source for cost reduction, 80 million Yuan in 2012, according to the district authorities. The system generates lists with status reports on the patients that the doctor is responsible for, and gives alert if there are abnormal test results, or if i.e. a diabetic patient should be called in for a check-up or test.

Figure 54. Information Infrastructure Summary from Changing Maternity and Child hospital



Source: Changnin Mother and Child Hospital

The hospital started the development of its hospital information systems in the late 90s. Mainly these were billing systems for the insurance system, based on DOS. In 2003-2006, the hospital installed different clinical support systems and the implementation of a local EMR.

For the hospital it has been a priority to develop means to handle processes of registration and admission in a user friendly and efficient manner. Consequently, in 2006-2009, they started using ICT actively in particular focusing on activating the patients themselves in the process through use of self-service terminals and online services and SMS to avoid waiting lines at the day of admission. Today, the hospital also uses social media to inform and educate their patients.

Today, the hospital uses the city's shared one mother and child record. Pregnant women conduct their first health check at the CHCs in week 12. Then an electronic medical record is produced. From the community health center the pregnant mother is transferred to specialist care in week 36. The mother/child record is then packed and sent as an EDI message or according to HL7 standards. This means that the information recorded at the hospital is made available for the community health centers through use of an identity card or an eID. While the hospitals work in their own systems, the information that is documented on the platform is in accordance with a standardized dataset which allows for vertical integration, automatically sending information from the hospital to the Shanghai Woman and Child Care Information Center. Digital information in pregnancy and birth record is gathered at a provincial level, then information is integrated vertically, up to a national quality/birth

register, from which quality indicators are developed to compare hospitals i.e. on the use of caesarian sections.

In the ward, there are two different work stations with each their log in, one for midwives and nurses and one for the physician with different interfaces according to the specific organizational role of the user. Nurses can use pads on their rounds. Using videoconferences they can call on a physician, who can do a “video visits” at bedpost through the nurse’s pad. Electronic charts, decision support tools, such as medication calculation and warnings against interaction problems, are part of the hospital EHR systems. Lab tests are scanned, and can be checked through any device which allows logon. With regard to future developments, much focus is on the continuous development and integration of clinical pathways into the EHR system.

As today, the patients do not have online access to their maternity record. They must therefore use the terminals at the hospital area to access their information and also carry with them the maternity record on paper throughout the pregnancy.

In general, privacy issues are not high on the agenda. It is possible to identify high risk patients (HIV/AIDS) in order to ensure extra precaution is taken. Only healthcare personnel with treatment responsibility have access to this information, and access is being logged. The information available in the hospital only involves pregnancy and birth. There is no information about family history or social problems of any kind.

### 18.2.6 Digital Services for Citizens

Figure 55. Picture from study trip: Terminals give patients access to health portal



By swiping their medical insurance card at a terminal standing in a community health center or a hospital, or by logging in at home through internet patients can access the following information stored at the city level:

- List of registered prior consultations
- Medical record

- Electronic booking (In the booking process, the patient will have access to updated waiting lists and information about individual doctors)
- Information about their medical insurance and the billing system
- Test results
- Prescription

Through the terminals at the community health centers and hospitals, patients can print out their test results and medication lists; they can also have a paper version of their medical record.

**Figure 56. Picture from study trip: Professional biographies of doctors displayed in the foyer to support the patients' self-booking.**



The citizen portal also gives access to general healthcare information and advice. There is currently no functionality for digital dialogue between patient and provider.

Patients can upload test results from self-monitoring devices to their EMR. The EHR system will remind the patient what medication to get and tests to take and what is eligible. This is done to activate patient, to have transparent process for quality improvement, and to make patient aware of costs for different interventions.

Regarding use patterns among patients, there is a clear age divide. Young people use the system to book appointments and manage their data on line. While the elderly uses the self-monitoring stations at the community healthcare centers along with the advice they receive from staff there.

### 18.2.7 Secondary Use of Data

The Health Statistics and Information Center of the Ministry of Health and its branches in provincial health bureaus routinely collect all patient information using ICD-10 classification. Information comes from the first page of patient medical records as reported by the Department of Medical Records in each hospital nationwide. Contents include demographic data, diagnosis, surgical records, length of stay, medical costs, etc. China's Health Statistics Year Book, published by the MOH, including the cost of 30 major diseases in hospitals at different levels.

With the healthcare reform, the focus on quality of care has increased. Efforts have been made i.e. against misuse of antibiotics, to increase drug quality and safety, development of clinical guidelines and pathways, and hospital accreditation.

The central government and healthcare organizations have set up several disease registries and patient registries that are now being used by specialized medical associations, medical interest groups or pharmaceutical companies to collect data. Governments at all levels actively use the information gathered in the EHR systems to monitor and evaluate a range of issues, from quality and safety to efficiency and performance, laying the groundwork for a more solid healthcare infrastructure in the future. Statistics on for example beds, costs, medication, whether the patient goes to more than one doctor with the same complaint. etc., can be viewed both on city, enterprise and personnel level. Through these overviews the authorities can follow up on i.e. policy compliance with regards to prescription of antibiotics, monitoring which doctors prescribe antibiotics according to guidelines. The monitoring activity also includes the ability to go into each and one EHR to oversee the quality of documentation. In this way, the system assists in monitoring policy on its way into practice.

The Shanghai RHIN generates a dashboard with waiting lists, logistics, and efficiency of treatment, medical expenses and costs of each of the district's 16 hospitals, each department and single doctors. Costs can be broken down on i.e. equipment and personnel and distributed on different diseases. Because all the information is collected on one platform, the authorities can also monitor patient trajectories, which construct valuable data for public health management.

The Changning district health bureau foresees that further development and use of database to produce more statistics that can help drive quality improvements will be a key area of development in the time ahead.

## Appendix A: Comparative Framework

Areas of interest	Action/service
<b>Governance, financing and organization</b>	<ol style="list-style-type: none"> <li>1. How to describe the governance structure in the healthcare sector – issues of prioritization and coordination?</li> <li>2. How is health and care services financed?</li> <li>3. How is the healthcare system organized?</li> <li>4. What characterizes the governance, financing and organization of eHealth in the broader context of healthcare?</li> <li>5. What user groups, technologies, professional groupings, regulatory regimes are included in the definition of eHealth?</li> <li>6. History, roadmap, status and challenges ahead?</li> <li>7. What systems are in place to monitor and evaluate eHealth initiatives?</li> <li>8. International cooperation?</li> </ol>
<b>Needs Assessment</b>	<p><i>ICT for integrated care</i></p> <ol style="list-style-type: none"> <li>1. How do the different actors in the healthcare system share information across levels, disciplines and roles?</li> <li>2. How is this information organized?</li> <li>3. How to find online and updated registrations of all the medication <i>prescribed</i> to a patient?</li> <li>4. How to find online and updated registrations of all the medication <i>used</i> by a patient?</li> <li>5. How to find information of different types of vaccinations given to a patient?</li> <li>6. How to share information in the multidisciplinary treatment team used for the management of several diseases? Have they all access to the same information?</li> <li>7. Developments on specific forms of shared EHR applications, i.e.:             <ol style="list-style-type: none"> <li>a. Shared care plan</li> <li>b. Summary care record</li> <li>c. Shared medication lists</li> <li>d. Shared maternity record</li> <li>e. Other</li> </ol> </li> </ol> <p><i>Terminology and codes</i></p> <ol style="list-style-type: none"> <li>1. Use of structured documentation, standardized terminology and standard codes, for diagnoses, laboratory, medical care etc.</li> <li>2. Education of personnel who is coding?</li> <li>3. What about information exchange of medical information, test result, pictures, documents etc.?</li> <li>4. Data retrieval. Archiving, filing?</li> </ol> <p><i>On the EHR systems in use (questions for observation during field trips)</i></p> <ol style="list-style-type: none"> <li>5. How do different professional groupings use the EHR systems and what for? (process support or retrospective documentation)</li> <li>6. How is content organized?</li> <li>7. How do healthcare professionals navigate in the system</li> <li>8. Does the system contain functionality that helps capture the complete patient trajectory</li> </ol>

	<ol style="list-style-type: none"> <li>9. Does the system have personalized workspace , tailored according to service area and professional status</li> <li>10. Does the EHR system contain functionality for decision support and how is it integrates with the patient record?</li> <li>11. How are process- and decision support tools designed and updated?</li> <li>12. Who is responsible for development, updating, training and support in use of the function?</li> <li>13. What are the experiences with ICT as support for knowledge intensive practice quality improvement, and patient administrative functionalities?</li> </ol>
<p><b>eHealth solutions for health personnel</b></p>	<p><i>Key documents, strategies and roadmaps</i></p> <p><i>National systems:</i></p> <ol style="list-style-type: none"> <li>1. Do you have any national eHealth systems? <ol style="list-style-type: none"> <li>a. Is the national eHealth system integrated with local systems?</li> <li>b. Has the national eHealth system replaced any local systems?</li> </ol> </li> <li>2. Is it mandatory for each enterprise to preserve information locally?</li> <li>3. Is all patient record information stored in national databases?</li> <li>4. Do you have any other solutions for sharing of information between organizations (IHE-XDS, document hotels etc.)?</li> </ol> <p><i>Local EHR systems:</i></p> <ol style="list-style-type: none"> <li>5. What is the main hospital information systems (EHR/PAS) supporting core workflow for doctors and nurses?</li> <li>6. Do you use systems from international vendors in the hospitals?</li> <li>7. What is the main health information system for GPs?</li> <li>8. What is the status for the use of national infrastructure and what are the future plans?</li> <li>9. How many of the institutions (percentage) are using national infrastructure?</li> <li>10. How are the institutions not connected to national infrastructure communicating (is use voluntary).</li> <li>11. Is data stored centrally or decentralized?</li> <li>12. Have you implemented PKI with a national CA? How is it organized (e.g. RA)?</li> <li>13. Are you using (direct) messaging? For What? Which standards are you using?</li> <li>14. Do you have a national service or messaging platform?</li> </ol> <p><i>Functionality of solutions</i></p> <ol style="list-style-type: none"> <li>15. How well are the areas supported – across levels and units <ol style="list-style-type: none"> <li>a. Access to relevant information</li> <li>b. Decision support</li> <li>c. Process support</li> <li>d. Hand-shake and handover of information</li> <li>e. Documentation (and only once for same information)</li> </ol> </li> </ol> <p><i>Privacy and security</i></p> <ol style="list-style-type: none"> <li>16. Who oversees information security on the different levels of the eHealthcare system?</li> <li>17. Who is the legal owner of the patient record information that is created, and is the authority regarding access and use of information?</li> <li>18. What are the policies for access in the (national eHealth) system?</li> <li>19. Does the (national eHealth) system support privacy by design principles,</li> </ol>

	<p>e.g. consent and reservation</p> <p>20. Have you had any security breaches?</p> <p>21. Have you had any problems with availability of the solutions?</p> <p><i>Information architecture</i></p> <p>22. Have you established a shared information model (national or regional)?</p> <p>a. Is it based on international standards?</p> <p>23. Which terminology standards are you using (e.g. SNOMED, ICD-10, ICPC)?</p> <p><i>Health registers</i></p> <p>24. What are the most important national health registers?</p> <p>25. How is information gathered in the registers?</p>
<b>Digital healthcare services for citizens</b>	<ol style="list-style-type: none"> <li>1. Key documents, strategies and roadmaps</li> <li>2. What are the key national initiatives, and how are online services for citizens governed, financed and organized?</li> <li>3. Does patient have access to health record from hospitals, GP, healthcare organizations etc.? If so, how is this information presented?</li> <li>4. Access to information about quality and safety of treatment and the capacity of hospitals, GP and care organization?</li> <li>5. Online booking systems for GP, hospital or other healthcare organization?</li> <li>6. What online services are planned for, and launched <ol style="list-style-type: none"> <li>a. Digital access to personal health information (patient record)</li> <li>b. Dialogue services between citizen and healthcare system</li> <li>c. PHR (Personal health records)</li> <li>d. Other</li> </ol> </li> <li>7. What models for private-public partnerships are at work?</li> </ol>
<b>Cost Benefit Analysis</b>	<ol style="list-style-type: none"> <li>1. Examples of relevant reference cases of cost benefit analysis (either ex ante or ex post) for national/regional eHealth investments? <ol style="list-style-type: none"> <li>a. In general?</li> <li>b. For EHR initiatives in particular?</li> </ol> </li> <li>2. Specific studies on eHealth benefits (quality, access, efficiency), e.g. <ol style="list-style-type: none"> <li>a. Reduction of errors (saved life/years)</li> <li>b. Enhanced adherence to best practices</li> <li>c. Enhanced decision making</li> <li>d. Enhanced efficiency/productivity of health personnel</li> <li>e. Efficiency/time savings for patients</li> <li>f. Optimized drug prescriptions</li> <li>g. Enhanced motivation to exercise</li> <li>h. Successful usage of QALY-methodology in some area</li> <li>i. Other</li> </ol> </li> <li>3. Specifics on the costs <ol style="list-style-type: none"> <li>a. Investment costs</li> <li>b. Operational costs</li> </ol> </li> <li>4. Changes in work processes – from the solution today to the solutions in the different future concepts – analysis approach/examples? Examples of successful model approaches on how to differentiate between separate concepts?</li> </ol>

	5. Model approach for prioritizing different functionality / different applications; how to set the boundaries/decision making within a concept?
<b>Strategy, goals and specifications</b>	<ol style="list-style-type: none"> <li>1. We are interested in papers or references (lessons learned, success factors and pit falls) concerning: <ol style="list-style-type: none"> <li>a. eHealth program/project investment strategy</li> <li>b. Early phase conceptual choices (e.g. degree of centralization, standardization etc.) – decision making/model approach</li> <li>c. Goal setting and level of ambition – which goals and why?</li> <li>d. Functional and technical demands – level of ambition</li> <li>e. Key Performance indicators (KPI) for eHealth programs/investment projects – which KPIs and why?</li> </ol> </li> </ol>
<b>eHealth competence</b>	<ol style="list-style-type: none"> <li>1. Is ICT a part in the basic education of healthcare personnel?</li> <li>2. Who conducts what form of research on EHR systems; universities, governmental authorities or commercial interests?</li> <li>3. What are the drivers for innovation in IT healthcare systems?</li> </ol>

## Appendix B: Summary of cases in table (In Norwegian)

	HELSE- OG OMSORGSYSTEM	E-HELSE KONSEPT	SEKUNDÆRBRUK AV DATA
<p><b>Danmark</b></p> <p>5,6 millioner innbyggere</p>	<p>Offentlig, skattefinansiert.</p> <p>Politisk fokus på kvalitet og helhetlige pasientforløp.</p> <p>5 regioner er hovedleverandør av tjenester inkl. sykehus og allmennleger (portvokterfunksjon). 98 kommuner ansvarlig for PLO, rehabilitering, og kronikere.</p> <p>Regionene krever ikke inn skatt, forhandler med kommuner og stat om budsjett og fellesoffentlige prosjekter.</p> <p><b>Sentrale e-helse aktører</b></p> <p><u>Sundhedsministeriet</u>: generelt ansvar for politikk og regelverk.</p> <p><u>National Sundhedsdata (NSI)</u>: Strategi, standardisering, drift og vedlikehold av nasjonale løsninger.</p> <p><u>Danske regioner, RSI</u> og <u>Kommunernes Landsforbund, KombIT</u>: Investering og implementering av IT i respektive sektorer.</p> <p>Generelt sterkt fokus på felles-offentlig eierskap og samarbeid om løsninger i nasjonal IT-arkitektur, eksempelvis er MedCom og Sundhed.dk eid av de tre aktørene i fellesskap, og innværende nasjonale strategi er en felles-offentlig strategi.</p>	<p>Den nasjonale IT-arkitekturen består av et helsenett, en tjenesteplattform, og en elektronisk portal for datatilgang.</p> <ul style="list-style-type: none"> <li>▪ <b>eJournalen</b> gir tilgang til sykehusjournaler</li> <li>▪ <b>pJournalen</b> gir tilgang til allmennelegejournaler – <i>pt ikke i drift!</i></li> <li>▪ <b>Fælles medicinkort</b> gir tilgang til lese/redigere medikamentinformasjon</li> </ul> <p>Opprinnelig var eJournal ett av to prosjekter som sammen skulle realisere en nasjonal EPJ løsning. <b>National Patient Index</b> skulle muliggjøre datasøk eJournalen skulle videreutvikles til <b>National Sundheds Journal</b> og sammenstille data fra index kildene i et koherent og intelligent brukergrensesnitt. Prosjekt stoppet i 2013 pga. kostnadsoverskridelser og (pågående) dragkamp om sentral vs. regional utvikling.</p> <p>Trenden i dag er regional konsolidering av sykehusenes IT-plattformer innenfor rammene av nasjonale standarder. Større felles prosjekt for Region Hovedstad og region Sjælland med innføring av EPIC.</p> <p><b>Sundhed.dk</b> gir pasienter og helsepersonell tilgang til kunnskapsressurser, journaldata og tjenester som Felles medisinkort, digital dialog og eBooking, samt administrative tjenester for virksomheter.</p> <p>Utstrakt bruk av MedCom elektroniske meldinger og henvisningshotell. MedCom og Sundhed.dk eies i fellesskap av stat, regioner og kommuner.</p>	<p>Har nasjonale helse- og kvalitetsregistre.</p> <p><b>eSundhed</b> gir tilgang til helsedata, indikatorer og sammenligninger fra regioner, sykehus og kommuner, samt data for kvalitetsstandarder, pakkeforløp, samhandlingsavtaler og aktivitetsdata for DRG-system.</p> <p>Nasjonal strategiplan vektlegger behovet for å flytte fokus fra innsamling, lagring og tilgang til data og over på forbedret <i>bruk</i> av data (også «frie» data) i form av analyser, prosess- og beslutningstøtte og monitoreringsløsninger som har en nytte og effekt i helsehverdagen.</p>

<p><b>Sverige</b></p> <p>9,5 millioner innbyggere</p>	<p>Offentlig, skattefinansiert (20 % privat finansiering, hovedsakelig egenandeler), relativt stor og voksende andel private tjenesteytere. Politisk fokus på samhandling, pasientrettigheter og likebehandling(Vårdgaranti),privatisering og konkurranse.</p> <p>21 län har hovedansvaret for helse- og omsorgstjenester, sykehus og primærtjenester som tilbys gjennom multidisiplinære vårdcentraler.</p> <p>Länene har etablert 6 regioner for samarbeid om tertiærtjenester.</p> <p>290 kommuner er ansvarlig for PLO, kronikere og skolehelsetjeneste.</p> <p>Bruk av private tjenesteytere er sterkt voksende. Ingen generelle standarder for tjenestepakker.</p> <p>Län og kommuner samarbeider innenfor Sverige Kommuner og länsting, som også forhandler med staten på vegne av sine medlemmer.</p> <p><b>Styringsmodell e-helse</b></p> <p><u>Socialministeriet</u> generelt ansvar for politikk og regelverk, og gjennom Socialstyrelsen ansvarlig for nasjonal informasjonsstruktur.</p> <p>eHälsomyndigheten får ansvar for eResept, medisindata og personlig helsearkiv.</p> <p><u>Kommuner og länsting</u> ansvarlig for investering og implementering av IKT i helse og omsorgssektoren. Samarbeider strategisk gjennom foretaket Inera AB som både er nasjonal bestiller og leverandør av e-helse. Generelt lite aktivitet på nasjonalt nivå, foruten</p>	<p>Den nasjonale IT-arkitekturen består av et helsenett, en tjenesteplattform, og en nasjonal kjernejournal for informasjonsutveksling på tvers av virksomhetsgrenser.</p> <ul style="list-style-type: none"> <li>• NPÖ peker til eksisterende helseinformasjon. Virksomhetene bestemmer selv hva de vil tilgjengeliggjøre.</li> <li>• 1117.se gir innbyggere tilgang til en rekke e-helse tjenester inkludert. online konsultasjoner og eBooking.</li> <li>• Pascal og Nationell Ordinationsdatabas skal sammen sikre helsepersonell tilgang til komplett legemiddelliste. Krever revisjon av lovverket, som er til behandling hos departement.</li> </ul> <p>Med lokal autonomi over IKT eksisterer et mangfold av EPJ løsninger og standarder nasjonalt. Trenden er regional konsolidering i länene.</p> <p>Det foreligger 3 alternative forslag for den videre utviklingen av nasjonale e-helse arkitektur i Sverige:</p> <ol style="list-style-type: none"> <li>1. SKL tar over eierskap til Inera og styrker derigjennom samarbeidet mellom kommuner, regioner og länsting på e-helseområdet, og deres investeringer i nasjonale fellesprosjekter.</li> <li>2. Den offentlige utredningen <i>Nåsta fas i e-hälsoarbetet</i> anbefaler å utvikle en nasjonal styringsmodell med en samhandlingsnemnd beslutningsmyndighet for e-helse. Tiltak på medisinsområdet foreslås prioritert.</li> <li>3. De tre største regionene har gjennom 3R programmet gått sammen om en kommersiell anskaffelse av en felles IT plattform med EPJ og PAS funksjonalitet for primær- og spesialisthelsetjenesten.</li> </ol>	<p>Sverige har om lag 90 nasjonale kvalitetsregistre og 4 kompetanse sentre som brukes aktivt for å understøtte monitorering og kvalitetsforbedringsarbeid. Inera publiserer data fra kvalitetsregistrene.</p> <p>Visjonen er å etablere et helhetlig kunnskapssystem som brukes aktivt på alle nivå for kontinuerlig læring, kvalitetsforbedring og administrasjon og ledelse av helsetjenesten.</p>

	<p>om medikament feltet.</p> <p>Inera gir ut handlingsplaner som medlemmer etterlever på frivillig basis.</p> <p>Sverige har gitt ut to fellesoffentlige e-helse strategier (2006;2010) som vektlegger lokalt/regional autonomi.</p>		
<p><b>Finland</b></p> <p>5,4 millioner innbyggere</p>	<p>Hovedsakelig offentlig, skattefinansiert, relativt stor andel private tjenesteytere.</p> <p>Politisk fokus på lik behandling, og integrasjon av helse- og velferdstjenester.</p> <p>Kommunene er autonomt ansvarlig for alle helse- og velferdstjenester, som organiseres i 166 primærhelsesentre og 20 sykehusdistrikt.</p> <p>PLO regnes som sosialtjeneste. Allmennleger er privatpraktiserende (portvokterfunksjon).</p> <p>Omfattende helsereform på gang, fem administrative regioner får ansvar for å tilby helse- og velferdstjenester finansiert av kommunene. Sterkere sentral styring innføres.</p> <p><b>Styringsmodell e-helse</b></p> <p>Helse- og sosialdepartementet: generelt ansvar for politikk og lovgivning, forventes å ta sterke grep om planlegging med SOTE-reformen.</p> <p><u>THL</u>: kompetansesenter med utstrakt operativt ansvar og koordinering, standardisering (inkludert nasjonal kodeserver).</p>	<p>Den nasjonale IT-arkitekturen tar utg.pkt. i en sterkt strukturert og sentralisert informasjonsmodell, interoperable EPJ systemer og et nasjonalt arkiv for lagring av helseinformasjon - KanTa. Informasjon mellom lokale EPJ-systemer og fellestjenester utveksles i form av strukturerte dokumenter. Terminologi, koder, klassifikasjoner oppdateres og tilgjengeliggjøres av en <b>nasjonal kodeserver</b>.</p> <ul style="list-style-type: none"> <li>▪ <b>eResept</b> lagrer alle data om resepter skrevet av leger og utlevert av apotek i et eResept datasenter.</li> <li>▪ <b>eArkiv</b> gir helsepersonell tilgang til pasientinformasjon som er lagret i KanTa via en webløsning som fungerer som en integrator. <b>eOversikt</b> gir innbyggeren tilgang til egen helseinformasjon på nett (godkjent av behandler).</li> <li>▪ <b>Digitalt Helsebibliotek</b> driftet av finsk legeforening</li> </ul> <p>Forventer regional konsolidering på EPJ-systemer i kjølvannet av den kommende strukturreformen. Stort anskaffelsesprosjekt for felles IT plattform for helse og velferdstjenester på gang i Helsinki (Apotti).</p> <p>Med utgangspunkt i reformfokus på integrasjon mellom helse- og velferdstjenester har flere byer (igangsatt) anskaffet IT-plattformer som kan dekke begge tjenesteområdene.</p>	<p>Har nasjonale helse- og kvalitetsregistre.</p> <p>Finsk legeforening (Duodecim) har utviklet et bredt sett beslutningsstøtteløsninger basert på strukturerte data fra EPJ og et script som sammen gir kontekst-sensitiv informasjon fra en sentral server direkte til lokal EPJ.</p> <p>Som et resultat er informasjonen lagret i KanTa semantisk interoperable slik at informasjon kan utnyttes til ulike formål. Det rommer et stort potensiale ift. Folkehelseovervåkning og studier av behandlingseffekter, basert på kombinasjon av sosioøkonomiske datasett og EPJ-data. Potensialet også for mer personlig oppfølging av helsestilstand, identifikasjon av risiko og tidlig intervensjon i forebyggingsøyemed.</p>
<p><b>Estland</b></p> <p>1,3 millioner</p>	<p>Offentlig, skattefinansiert, utviklet i kjølvannet av løsrivelsen fra Sovjet Unionen.</p> <p>Ambulansetjeneste drives av staten. Sykehus</p>	<p>Estisk e-helse er en del av et større digitalt velferdssystem - X-road. To nøkkelkomponenter; eID og en fleksibel tjenesteplattform som kan integreres med ulike databaser og applikasjonssystemer.</p>	<p>Ingen spesifikk strategi eller tiltak nevnt i innhentet dokumentasjon.</p>

<p>innbyggere</p>	<p>hovedsakelig (felles-)offentlig eie, men opererer som privat foretak. Dagbehandlings er for det meste private. Fastleger er privatpraktiserende (delvis portvokterfunksjon). Generelt mangel på sykepleiere.</p> <p><b>Sentrale e-helse aktører</b>  <u>Arbeids- og helseministeriet</u>: styringsansvar delt mellom avd. helseinformasjon og analyse (infrastruktur, analyse og indikatorer) og avd. e-helse (komponenter og tjenester), delt ansvar for registre.  <u>eHealth Foundation (e-tervis)</u>: samarbeid mellom sektoraktører og sentrale myndigheter, ansvar for utvikle, promotere og forvalte nasjonalt e-helsesystem, standardisering, kompetansesenter.</p>	<p>Det estiske e-helse konseptet bygger på en Health Information Exchange (HIE) plattform. Virksomhetene har sine egne lokale EPJ installasjoner og er pålagt ved lov å sende 14 dokumenter på standardisert format til det sentrale informasjonslageret som tilgjengeliggjør:</p> <ul style="list-style-type: none"> <li>▪ <b>eResept</b>-modul med en felles database i bunn</li> <li>▪ <b>EPJ</b>-informasjon, kritisk info, og PACS</li> <li>▪ <b>Pasient portal</b> gir tilgang til EPJ data, selvmonitoreringsdata, pasientforum, screening-påminnelser, virtuell helsesjekk og egenomsorg</li> </ul>	
<p><b>Nederland</b> 17 millioner innbyggere</p>	<p>Markedsregulert, felles basisforsikring skattefinansiert, obligatorisk toppforsikring privat finansiert.  Myndighetene utformer lovverk og overser kvalitet, tilgjengelighet og kostnader ved å forhandle om innholdet i basis helseforsikring.  Forsikringselskaper tilbyr forsikring og forhandler med tjenestetilbydere om pris, volum, kvalitet og kostnader.  En sær hybrid konstellasjon av offentlige, private, frivillige aktører tilbyr helsetjenester.  Allmennleger er privatpraktiserende (portvokterfunksjon).</p> <p><b>Sentrale e-helse aktører</b>  <u>Ministry of Health, Sports and Welfare</u>: minimal</p>	<p>Det nasjonale EPJ infrastrukturen – AORTA ble lansert i 2006 som en indexbasert (Health Information Exchange (HIE) løsning basert på desentralisert lagring for utveksling av:</p> <ul style="list-style-type: none"> <li>▪ <b>Pasientsammendrag</b> med informasjon om allergier, medisiner, fastlege EPJ.</li> <li>▪ <b>Samstemt medisinliste</b></li> <li>▪ <b>Egenjournal</b> (PHR) med innsyn i EPJ</li> </ul> <p>Prosjektet skrinlagt i 2011 som følge av opphetet politisk debatt om personvern. I dag driftes HIE-løsningen av en sektorgruppe. Tilknytting er frivillig og løsningen har foreløpig begrenset utbredelse. Kun pasientsammendrag og e-resept som fellestjenester.</p> <p>Sentrale myndigheter konsentrerer innsatsen om utvikling og spredning av standarder (ikke-bindende). Politisk sonderinger pågår rundt mulig bruk av et insentivregime inspirert av det Amerikanske</p>	<p>Nederland har ingen nasjonale personidentifiserbare registre.</p> <p>Nederlandsk legeforening har strukturert allmennlegejournalene og integrert beslutningsstøtte for medikamenthåndtering. Utvikler integrasjon av retningslinjer og beslutningsstøtte basert på standardiserte forløp.</p>

	<p>rolle. Regulerer (særlig EU-direktiv), retningslinjer, refusjonsordninger.</p> <p><u>NICTIZ</u>: Kompetansesenter med ansvar for standardisering og rådgivning.</p> <p><u>NiA</u>: Sektorallianse med ansvar for nasjonal handlingsplan for e-helse.</p>	<p>«Meaningful use».</p> <p>Høy grad av lokal innovasjon har resultert i et stort antall digitale løsninger for innbyggere, men ingen felles, nasjonale initiativ.</p> <p>Nasjonal pasient- og konsumentorganisasjon utvikler PHR løsning med fokus på medikamenthåndtering.</p>	
<p><b>England</b></p> <p>53 millioner innbyggere</p>	<p>Offentlig, skattefinansiert. I kjølvannet av et politisk skifte i 2010 initieres radikal, konservativ/liberal reform. 211 clinical commissioning groups planlegger og kjøper helsetjenester. Målet er å skille det politiske fra det operative. De fleste tjenestene, som sykehus, forvaltes av en (offentlige eller privat) stiftelse (trust). Stiftelsene undergår nå privatisering. Allmennleger er privatpraktiserende (portvokterfunksjon).</p> <p>Liberaliseringen av NHS har resultert i et relativt fragmentert system, uten et sterk styrende og koordinerende kraft. Myndighetene fokuserer på utvikling av felles rammeverk for kvalitet og kvalitetsmålinger som et organiserende prinsipp, og en potensielt integrative kraft.</p> <p><b>Sentrale e-helse aktører</b></p> <p><u>Department of Health</u>: Minimal rolle utover generell politikkutvikling og lovgivning.</p> <p><u>The Patients and Information Directorate</u>: NHS e-helse strategi, standardisering og informasjonsforvaltning.</p> <p><u>Health &amp; Social Care Information Center</u>: ansvarlig for samle, linke, lagre og publisere helseinformasjon og for leveranse av nasjonale løsninger.</p>	<p>The National Program for IT igangsettes i 2009 med planer om et nasjonalt EPJ-system med sentral finansiering og organisering rundt fem regionale med hvert sitt EPJ-system og en sentral enhet. Som følge av store utfordringer forbundet med scope, planlegging, kostnadsoverskridelser og manglende gevinstrealisering stoppes programmet i 2011. Ny konservativ/liberal regjeringen snur kurs, forlater sterk sentralstyring til fordel for minimal statlig intervensjon og stimulering lokal innovasjon.</p> <ul style="list-style-type: none"> <li>▪ <b>Demografisk dataregister</b> muliggjør sikker identifikasjon og tilgangsstyring til NHS systemene.</li> <li>▪ <b>SPINE</b>-plattformen gir tilgang til felles nasjonale applikasjoner og tjenester, herunder:</li> <li>▪ <b>Kjernejournal</b> med kritisk info fra fastleger.</li> <li>▪ <b>Choose and book</b> et nasjonalt henvisningssystem som lar pasienten velge behandlingssted- og tid.</li> <li>▪ Nasjonal <b>PACS</b>-løsning.</li> <li>▪ <b>E-resept</b></li> <li>▪ Sentrale myndigheter anskaffer EPJ-systemer for allmennleger. <b>GP2GP</b> muliggjør utveksling av EPJ-er mellom allmennlegepraksiser.</li> <li>▪ <b>NHS mail</b> muliggjør meldingsutveksling.</li> <li>▪ <b>NHS Choice</b> gir pasienter tilgang til helseinformasjon og informasjon om rettigheter og behandlingssteder, inkludert kvalitetsindikatorer. Pasienter kan bruke Choose and Book etter innlogging.</li> </ul>	<p>Har nasjonale helse- og kvalitetsregistre. NHS har samlet data fra sykehusinnleggelse siden 1980-tallet. For å få et mer komplett bilde over pasientforløp igangsatt Care.data-prosjekt med formål å samle inn informasjon fra fastlegenes systemer og lagre disse sentralt. Politisk debatt rundt personvern og kommersiell bruk av helsedata har satt en midlertidig stopper for prosjekt.</p>

		Et stimuleringsfond er etablert med fokus på standarder for interoperabilitet og utbredelse av de nasjonale felles tjenestene.	
<b>Skottland</b> 5,5 millioner innbyggere	<p>Offentlig, skattefinansiert helsesystem. Politisk fokus på integrasjon av helse og omsorg, samt kvalitet- og resultatstyring. 14 regionale Healthcare Service Boards ansvarlig for helse til sine innbyggere. Primær- og spesialisthelsetjenesten er integrert. Primærhelsetjenesten opererer i allmennelegepraksiser (portvokterfunksjon), mens sykehusene eies av NHS Scotland. Private og frivillige organisasjoner er hovedleverandører av PLO.</p> <p>Høy grad av regional autonomi medfører store regionale forskjeller i den faktiske organisering av tjenesten.</p> <p><b>Sentrale e-helse aktører</b>  <u>Head of eHealth Strategy and Policy</u> I den skotske regjeringen er ansvarlig for nasjonal e-helsestrategi.  <u>eHealth Directorate</u> leder nasjonale programmer for strategiutvikling, arkitektur, og informasjonssikkerhet.  <u>eHealth Leads Group</u> består av ADene i NHBene og møtes månedlig. NHBene investerer i e-helse og gruppen bidrar til nasjonal koordinasjon.  <u>National Information Systems Group</u> nasjonal bestillings og driftorganisasjon.  <u>Clinical Change Leadership Group</u> sikrer</p>	<p>Den nasjonale IT-arkitekturen bygger på et desentralisert konsept. Heller enn å bygge ett, overgripende nasjonalt system, legges det opp til en inkrementell og pragmatisk tilnærming der en bygger linker mellom eksisterende systemer og fyller hull. Det er et sterkt fokus på samstyring og deltakelse fra sluttbrukere. Konseptet består av en klinisk portal som presenterer informasjon fra ulike IKT systemer.</p> <ul style="list-style-type: none"> <li>▪ <b>SCI Gateway</b> og <b>SCI Store</b> system for meldingsutveksling.</li> <li>▪ <b>Nasjonal PACS løsning</b></li> <li>▪ <b>Kjernejournal</b> kopierer data fra eksisterende kilder og tilgjengeliggjør for lesing. Egen modul for kronikere (KIS).</li> <li>▪ <b>Rammekontrakt for EPJ system for primærhelsetjenesten</b> med valg mellom 2 leverandører.</li> <li>▪ <b>Nasjonal PAS system</b></li> <li>• <b>ePharmacy</b> eResept, modul for oppfølging av kronikere, betalingsløsning.</li> </ul>	<p>The Information Service Division er ansvarlig for nasjonale helse- og kvalitetsregistre.</p> <p>Etablert en nasjonal forskningsplattform for analyse av EPJ informasjon (SHIP).</p>

	brukerinvolvering i programmene.		
<b>Spania</b> 46,5 millioner innbyggere	Nasjonal myndighet ansvarlig for koordinering av folkehelsearbeid og helsetjenester, utvikler generell helselovgivning og politikk, internasjonale avtaler og regulering av farmasøytiske produkter. 17 autonome regioner har ansvar for hvert sitt, hovedsakelig offentlig, helsesystem. Etter omfattende reformer på 80-90 tallet fikk fastleger portvokterfunksjon. Primærhelsetjenester ytes i multidisiplinære helsesentre.  <b>Sentrale e-helse aktører</b> Regionene er ansvarlig for investeringer og implementering av e-helse. NHS ansvarlig for nasjonal interoperabilitet.	Et ID kort skal brukes til å identifisere pasient og Informasjon lagret om denne.  Et nasjonalt helsenett og en sentral node er «switch-point» for informasjonsutveksling mellom ulike databaser og regionale helseinformasjonssystemer (folkeregister, profesjonsregister, sosialforsikring, eResept, og EPJ systemer). Systemet baserer seg på meldingsutveksling (SOA arkitektur).	
<b>Andalucia (Spania)</b> 9 millioner innbyggere	Offentlig, skattefinansiert. I praksis finansiert og organisert som én organisasjon av regionale styresmakter. Det gjør at alle trekker i samme retning, fordi kostnader og gevinster i stor grad er delt. Primærhelsestasjoner med allmennleger (portvokterfunksjon) PLO er ikke inkludert i helse. Sykehus er også offentlig.  <b>Sentrale e-helse aktører</b> Sterkt sentralisert regional styring av sektor inkludert e-helse. <u>Junta de Andalucia</u> : det regionale helseministeriet gir politisk retning.	Diraya – e-helsesystemet i Andalucia - er en egenutviklet Health Information Exchange (HIE) løsning med felles sentraliserte databaser og integrasjon mot ulike EPJ-moduler som henter semi-strukturert informasjon fra 36 ulike systemer. <ul style="list-style-type: none"> <li>▪ 1 EPJ-system for primærhelse og 1 EPJ-system for sykehus – systemene utveksler informasjon.</li> <li>▪ <b>eResept</b></li> <li>▪ <b>PACS</b></li> <li>▪ <b>eBooking</b></li> <li>▪ <b>ClicSalud</b> gir pasienten tilgang til EPJ, eBooking, telefontjeneste og generell helseinformasjon</li> </ul> Det er pasienten, i samråd med fastlege, som bestemmer hvilken informasjon som skal deles. Et skreddersydd vindu gir behandlere oversikt over den mest relevante fellesinformasjonen.	Spania har nasjonale helse- og kvalitetsregistre.  Diraya genererer rapporter som gjør det mulig å identifisere risikopasienter iht. spesifikke kriterier (f.eks. «røyker+hjertesykdom»), monitorere ventetidsfrister og bruk av medikamenter (særlig antibiotika og kostbare eller medikamenter forbundet med høy risiko). Noe beslutningsstøtte er utviklet på disse områdene, generelt skjer det nå en rask utvikling.  Rapportene brukes også som grunnlag for resultatbasert finansiering av virksomhet og

	<p><u>Servicio Adaluz de Salud</u>: administrerer hele helsesektoren og eier hele IT-systemporteføljen. Virksomheter har ikke egne strategier, budsjetter, eller anskaffelser på IT-siden.</p> <p><u>CITAWEB</u>: Ansvar for integrasjoner og sertifisering.</p>		<p>enkeltbehandler i henhold til regionalt og nasjonalt definerte KPIer.</p>
<p><b>USA</b></p> <p>316 millioner innbyggere</p>	<p>30 % av befolkningen har offentlig helseforsikring gjennom inntekstfinansierte programmer. Offentlig finansierte programmer er Medicare (elder og funksjonshemmede) og Medicaid (lavinntekt og funksjonshemmede), det militære helsesystemet (DoD) og helsesystemet for krigsveteraner (VHA). 16 % er uten helseforsikring.</p> <p>Den kontroversielle «Obamacare reformen er under implementering. Hovedmål er å sikre at hele befolkningen har helseforsikring.</p> <p>Offentlig og privat innkjøp av tjenester til helseorganisasjoner i tråd med reguleringer fra føderale, statlige, og lokale myndigheter og private regulatoriske organisasjoner.</p> <p><b>Sentrale e-helse aktører</b></p> <p>The National Coordinator for Health Information Technology er hovedansvarlig for e-helse på føderalt nivå. Publiserte nasjonal strategi. Koordinerer utbredelse av sertifiserte e-helse løsninger nasjonalt. Promoterer bruk av nasjonale (interoperabilitet) standarder.</p> <p>Føderale myndigheter har sterkt fokus på å sikre medvirkning og aksept blant et bredt sett av</p>	<p>Virksomhetene er autonome i valg av EPJ systemer. Mange aktører har fortsatt ikke implementert EPJ. Stor variasjon i kvalitet blant systemene som er tatt i bruk. Føderal incentivordning - Meaningful Use - skal sikre at leverandører utvikler EPJ systemer i tråd med nasjonale standarder og at virksomheter anskaffer sertifisert programvare.</p> <p>Nationwide Health Information Network (NHIN) er ett sett med standarder, tjenester og policy som skal sikre sikker informasjonsutveksling over internettet. Flere ulike komponenter former grunnlaget for NHIN – autentisering og sertifisering, språk og meldingsstandarder, leveranseprotokoller, adresseregistre, rammeverk for tillit og sikkerhet. Med <a href="#">the State HIE Cooperative Agreement Program</a> finansierer føderale myndigheter stater som bygger ut HIE kapabilitet innad og mellom stater. Tre former er i bruk:</p> <ul style="list-style-type: none"> <li>- <a href="#">Directed Exchange</a> – utveksle sikker informasjon mellom virksomheter for å understøtte samhandling.</li> <li>- <a href="#">Query-based Exchange</a> – søke og be om informasjon fra andre virksomheter, særlig ved uplanlagte hendelser.</li> <li>- <a href="#">Consumer Mediated Exchange</a> – pasienten kontrollerer bruk av helseinformasjon blant virksomheter.</li> </ul>	<p>Ett sentralt element i den føderale e-helse strategien er visjonen om å bruke digitale løsninger for å muliggjøre et økosystem for kvalitetsforbedring som promoterer bedre helse og omsorg, bedre kommunikasjon, og transparens, rask tilgjengeliggjøring av ny kunnskap for alle aktører og reduksjon av byrden forbundet med datainnsamling og rapportering for alle tjenesteytere.</p>

	interessentgrupper på alle nivåer politikutviklingen.		
<b>Kaiser Permanente (USA)</b>  9 millioner medlemmer	<p>Privat, non-profit totalleverandør av helsetjenester; forsikring, innkjøp og tjenesteyting. Opererer med en forskuddsbaserte innbetalingsmodell som er et sterkt incentiv for forebyggende arbeid.</p> <p><b>Sentrale e-helse aktører</b> Utover styringsmodellen for organisasjonen som helhet, har KP også en Managing Director for HealthConnect med ansvar for strategisk planlegging, utvikling og implementering. Det er også nedsatt ulike sammensatte grupper av klinikere, regionalt og nasjonalt, som arbeider med å utvikle nye organisasjonsmodeller, retningslinjer, mm som inngår som del av kunnskapsgrunnlaget for HealthConnect.</p>	<p>KP HealthConnect er en sammenkopling av en IT-plattform levert av Epic og en omfattende organisasjonsutviklingsprosess med fokus bl.a. på evidensbasert praksis, helhetlige pasientforløp og forebyggende arbeid. Konseptet baserer seg på felles datastruktur og felles klinisk innhold som er utviklet globalt, og lokale tilpasninger og løsninger utviklet regionalt som sikrer at løsningen gjenspeiler lokal arbeidsflyt. IT-plattformen gir sanntidstilgang til helseinformasjon på tvers av organisasjonen; mellom tjenestenivå og mellom de tre organisatoriske enhetene. Applikasjonssuiten inneholder bl.a.:</p> <ul style="list-style-type: none"> <li>▪ <b>Integrasjon mellom EPJ og PAS</b></li> <li>▪ <b>Beslutnings- og prosessstøtte</b></li> <li>▪ <b>E-resept</b></li> <li>▪ <b>Sikker e-post</b></li> <li>▪ <b>“SmartSets” og “Order Sets”</b> integrerer evidensbasert rettleiding for tester og medikamenter i EPJ-systemet.</li> <li>▪ <b>Panel Support Tools</b></li> <li>▪ <b>MyHealth Manager</b> gir pasienter tilgang til EPJ, oppsummeringer og påminnelser etter konsultasjoner, digital dialog, eBooking, generell helseinformasjon, vurderingsløsninger for egen helse, 24/7 call center.</li> </ul>	<p>Med utgangspunkt i felles IT-plattform er KP kjent som ledende innen kunnskapsbasert praksis.</p> <p>Investerer betydelige organisatoriske ressurser i å utvikle gode læringssirkler der helsedata fungerer som felles «råvare». Informasjon fra KPs database – gjerne i kombinasjon med andre informasjonskilder som kvalitets- og helseregistre - gjøres til gjenstand for analyse, forskning og kliniske vurderinger rundt enkeltpasienter, pasientgrupper, eller hele paneler av medlemsmassen. Resultatet av denne analytiske virksomheten inkluderes i KPs helsebibliotek, som igjen danner grunnlag for utvikling av ny pasientforløp, nye organisasjonsformer (team basert behandling), prosess- og beslutningstøtte integrert i EPJ-systemene. Målet er at ny, evidensbasert kunnskap raskt skal bli en del av helsefaglig praksis.</p> <p>EPJ-informasjon brukes for å øke screening og behandlingsrater. <b>Proactive office encounter program</b> lar kliniske team samarbeide for å identifisere muligheter til å engasjere pasienter og forbedre kronisk behandling ledelse på tvers av tjenester.</p> <p>Administrativ og klinisk ledelse kan trekke ut</p>

			rapporter som flagger gap mellom evidensbasert anbefaling og faktisk tjenesteyting, fra disse kalkuleres månedlige resultatscores for organisasjon, virksomheter, enkeltbehandlere og behandlingsteam. <b>The Big Q</b> integrerer et bredt sett av KPIer, f.eks. på klinisk kvalitet, brukertilfredshet, pasientsikkerhet og risikohåndtering og viser dette i ett helhetlig overblikk.
<p><b>Veteran Health Administration (USA)</b></p> <p>8,5 millioner medlemmer</p>	<p>VHA er ansvarlig for USAs største integrerte helsesystemet. VHA er skattefinansiert og tilbyr helse og sosialtjenester til krigsveteraner og deres familier.</p> <p>Tjenester tilbys gjennom et nasjonalt nettverk bestående av 151 medisinske sentre, 820 helsesentre.</p> <p><b>Sentrale e-helse aktører</b></p> <p>Tok tidlig på 2000-tallet sterkt sentralt grep om styringen av organisasjonen, IKT-systemene inkludert. I dag fungerer <u>Chief Information Officer</u> er ansvarlig for visjon, ledelse, operasjoner og gjennomføring av IKT prosjekter. <u>The Office of Information and Technology</u> gir strategisk og teknisk retning og råd, og retningslinjer for å sikre innovasjon og effektiv ressursbruk iht føderale reguleringer.</p>	<p>VHA har utviklet et integrert helseinformasjonssystem – VistA – bygd rundt en EPJ løsning. VistA er bygd fra bunnen med et klinisk fokus ved at klinikere har blitt opplært som programmerere, og deltakere i utviklingsprosjektet. Programmet er utviklet basert på open source teknologi. VistA består av omlag 160 integrerte software moduler for klinisk, finansiell og infrastruktur funksjoner. VistA har ikke et betalingssystem siden helsetjenester er gratis for VHA medlemmer.</p> <ul style="list-style-type: none"> <li>▪ <b>Computerized Patient Record System</b> er et client–server grensesnitt for å lese og oppdatere EPJ består bl.a. av A Real-Time Order Checking System, Clinical Notification gir alarm ved viktige hendelser, varsler om allergiske reaksjoner eller nye behandlinger, klinisk ordreset, sykehistorikk fra andre lokasjoner.</li> <li>▪ <b>Clinical Reminder System</b> understøtter forebyggende arbeid.</li> <li>▪ <b>Barcode Medication Administration</b></li> <li>▪ <b>VistA Imaging System</b> integrerer ikke-tekstlige data i EPJen.</li> <li>▪ <b>MyHealthVet</b> web-basert PHR med tilgang til informasjon om rettigheter og tjenester, samt egen EPJ.</li> <li>▪ <b>VA Blue Button</b> lar pasienter generere og laste ned elektronisk fil med pasientens helseinformasjon fra <i>MyHealthVet</i>.</li> </ul>	

		<ul style="list-style-type: none"> <li>▪ <b>VA Continuity of Care Document</b> nøkkelinformasjon som kan deles mellom tjenesteytere for å understøtte samhandling.</li> </ul> <p>VistA 4 skal lanseres innen 2018 og skal bygge på modulær og utvidbar arkitektur basert på design prinsipper som SOA, Open Architecture, agil utvikling, og robust IT Infrastruktur med Cloud-first.</p>	
<p><b>Canada</b></p> <p>35 millioner innbyggere</p>	<p>Offentlig skattefinansiert helsesystem med hovedsakelig private tjenesteleverandører. Føderale myndigheter ansvarlig for finansiering, mens provinsene organiserer helsetjenesten gjennom regionale helsemyndigheter. Desentraliseringen av tjenesteproduksjon resulterer i svært store variasjoner i pasientforløp, men ikke uvanlig å starte hos en allmennlege (portvokterfunksjon). Ingen føderale politiske reformer siden 2005, provinsene i hovedsak organisering av RHAer og pasientopplevd kvalitet og effektivitet.</p> <p><b>Sentrale e-helse aktører</b></p> <p>Uten et sentralt organ for planlegging, skjer pan-canadiske samarbeid som regler gjennom komitearbeid eller sektorspesifikke byråer med avgrenset mandat. <u>Canada Health Infoway</u> er etablert av føderale myndigheter som sammen med provinsene og territoriene styrer stiftelsen i arbeidet med å utvikle et nasjonalt EPJ system. Infoway investerer i felles nasjonalt rammeverk for EPJ systemer iht. regionale strategier og eksisterende løsninger. Deltar i prosjektplanlegging og monitorerer regional implementering og leveranse kvalitet.</p>	<p>Regionene er autonom i investering og implementering av IKT-systemer. For de fleste regionene er EPJ programmet kun en del av deres e-helse strategier. Målet med det nasjonale EPJ løsningen er å gi autorisert helsepersonell tilgang til helseinformasjon uavhengig av tid og sted. Infoway som et virkemiddel for et interoperabelt e-helse system arbeider på to nivåer, utvikler nasjonal infrastruktur for informasjonsutveksling og finansierer regionale e-helseprosjekter som er kompatible med nasjonal infrastruktur og standarder.</p> <ul style="list-style-type: none"> <li>• <b>Pasientregister og helsepersonell register</b> – etablert i hver region, identifiserer pasienter og autoriserer personell.</li> <li>• <b>Felles medisinaliste</b></li> <li>• <b>Felles Lab system</b></li> <li>• <b>Felles bildearkiv</b></li> <li>• <b>Nasjonalt modell for endringsledelse</b></li> <li>• <b>Digitale innbyggertjenester</b> inkluderer bl.a. eBooking, eKonsultasjon, Pasientportaler, tilgang til EPJ, selv-monitorering, og fornying av resepter.</li> </ul> <p>Viktig å merke seg at disse ulike komponentene ikke er nasjonalt utbredt, det er betydelig regional variasjon i implementering og bruk av digitale løsninger.</p>	<p>Regionalt samles det inn detaljerte administrative data, mens det på føderalt nivå samles folkehelsesdata både gjennom nasjonal census hvert femte år, og pasientrapporteringer, og direkte malinger i befolkningen.</p> <p>Canadian Institute for Health Information identifiserer og definerer nasjonale helse indikatorer og rammeverk, koordinerer utviklingen og forvaltning av nasjonale data standarder, utvikler og forvalter helsedatabaser og registre, og publiserer helsedata gjennom forskningsrapporter. CIHI forvalter 27 databaser og kliniske registre.</p>

<p><b>Australia</b></p> <p>23 millioner innbyggere</p>	<p>Føderale myndigheter krever inn skatter og finansierer helsesystem, mens stater og territorier administrerer tjenester. Helsetjenester finansieres i kombinasjon av føderale, stat og territoriale myndigheter, private forsikringsselskaper og konsumenter.</p> <p>Heletjenester leveres gjennom et komplekst nettverk av offentlige og private tilbydere. Privat sektor leverer mesteparten av primærhelsetjeneste, spesialisthelsetjeneste, og driver sykehus. Stater og territorier driver sykehus med gratis tjenester og leverer helsetjenester i nærmiljøene. Myndigheter har generelt redusert sin rolle i helsetjenesteyting for å øke andelen av private og veldedige aktører.</p> <p><b>Sentrale e-helse aktører</b>  <u>National eHealth Transition Authority (NEHTA)</u> finansieres av stater, territorier og føderale myndigheter, og har inntil 2015 hatt ansvaret for standarder og terminologier, og pasient og personell id. Er nå under utvikling, og ny nasjonal styringsmodell under oppbygging.</p>	<p>Virksomheter velger fritt IKT systemer, det skaper utfordringer med en stor og voksende portefølje av e-helse initiativer som ikke er koordinerte eller interoperable. Mangelen på nasjonal strategi for helse generelt, gjør det utfordrende å finne mål og prioriteringer som en kan definere og mobilisere rundt e-helse som politisk virkemiddel. Kompleksiteten i organiseringen av helsetjenesten gjør det utfordrende å finne gode samarbeidsmodeller for e-helse.</p> <p>Den nasjonale løsningen Personally Controlled EHR er etablert som en portaltjeneste. Erstatte ikke regionale EPJ systemer, men gjør vha meldingsutveksling et standardisert sammendrag av relevant informasjon tilgjengelig. Pasienten kontrollerer hvilken informasjon som til enhver tid skal være tilgjengelig, og for hvem.</p> <ul style="list-style-type: none"> <li>• <b>Shared Health Summary</b> – diagnoser og tilstander, allergier, medisiner.</li> <li>• <b>Event Summary</b> – sammendrag fra konsultasjoner</li> <li>• <b>Hospital Discharge Summary</b></li> <li>• <b>Specialist letter</b></li> <li>• <b>eReferral Letter</b></li> <li>• <b>Prescription and dispensing information</b></li> <li>• Pasientmodul for å registrere personlig informasjon og notater</li> </ul>	
<p><b>New Zealand</b></p> <p>4,5 millioner innbyggere</p>	<p>Offentlig, hovedsakelig skattefinansiert. 21 District health boards (DHBs) organiserer mesteparten av helsetjenesten. DHB eier sykehus. Allmennleger (portvokterfunksjon) og spesialister er privatpraktiserende.</p> <p><b>Sentrale e-helse aktører</b></p>	<p>New Zealand's IT-arkitektur er en HIE-løsning på topp av regionalt konsoliderte IT-plattformer bestående av ulike moduler med klart definerte roller og grensesnitt og felles regionalt datalager. Informasjonsdeling på tvers av regioner sikres ved at løsningene må etterleve definert nasjonal arkitektur og standarder for interoperabilitet. Det er utviklet en felles informasjonsmodell for sektoren, denne definerer endemålet for utviklingen av et nasjonalt e-</p>	<p>Har nasjonale helse- og kvalitetsregistre. Ingen spesifikke planer om sekundærbruk av data i inneværende strategi.</p>

	<p><u>Ministry of Health Major IT Projects committee:</u> Prioriterer offentlige budsjetter og overser leveransen av nasjonale infrastrukturprosjekter.</p> <p><u>Information Directorate.</u> Ansvar for standarder og forvaltning av felles systemer.</p> <p><u>National eHealth Board:</u> Hovedansvar for e-helse strategiplan.</p> <p><u>Primary health care IT Governance Group:</u> Sikrer at primærhelseperspektivet hensyntas i alle regionale og nasjonale prosjekter.</p> <p><u>DHB CEO group:</u> Ansvar for å utvikle og implementere nøkkelprosjekter i hver sin region.</p> <p><u>Sector Architect Group:</u> Utvikler nasjonal og regional arkitektur.</p>	<p>helsesystem.</p> <p><b>Nasjonale fellesløsninger</b></p> <ul style="list-style-type: none"> <li>• <b>Electronic Shared Care Record View</b> gir oversikt over all relevant pasientinformasjon, også på tvers av regioner.</li> <li>• Virksomhetsstøttende systemer</li> <li>• <b>Felles behandlingsplan for gravide/mødre</b></li> <li>• <b>Felles pleieplan</b> for pasienter med komplekse og langvarige oppfølgingsbehov</li> </ul> <p><b>Regional IT plattform</b></p> <ul style="list-style-type: none"> <li>• <b>PAS</b></li> <li>• Webbasert <b>klinisk arbeidsflate</b></li> <li>• <b>Klinisk datalager</b> med oppdatert medikamentinformasjon, testresultater, radiologiske rapporter, behandlingsplaner, pasientbrev, henvisninger og epikriser.</li> <li>• <b>GP2GP</b> utveksler EPJ-er mellom allmennleger</li> <li>• <b>eResept</b> og <b>samstemmingsmodul</b> (nasjonal utbredelse 2016)</li> <li>• <b>Pasientportal</b> gir tilgang til EPJ, digital dialog, eBooking, og reseptfornyning. (Pasientportaler er kun tilgjengelig i enkelte DHBs)</li> </ul> <p>Meldingsutveksling er tilnærmet fullt utbredt.</p>	
<p><b>Kina</b></p> <p>1,4 milliarder innbyggere</p>	<p>Helsetjenester finansieres av offentlige midler, privat forsikring og egenandel. Tre typer offentlig helseforsikring, en for ansatte bosatt i by, bosatt i by men ikke i arbeid, bosatt i rurale områder. Store utfordringer knyttet til ulik dekningsgrad mellom by og land. Forsøk på å innføre modell for primærhelsetjeneste med fastlege som portvokter for å avta press på sykehussektor.</p>	<p>Det kinesiske 3521-programmet har som mål å etablere et nasjonalt EPJ system som lagrer informasjon om befolkningens livssyklus.</p> <p>- plattform med tre nivåer for forvaltning av helseinformasjon; nasjonal, provins, distrikt som skal håndtere ulike behov for informasjonsutveksling på ulike nivåer.</p> <p><b>5 –tjenesteområder etableres nasjonalt:</b></p> <ul style="list-style-type: none"> <li>▪ Folkehelse</li> </ul>	

		<ul style="list-style-type: none"> <li>▪ Helsetjeneste</li> <li>▪ Kontrollsystem for medikamentområde</li> <li>▪ System for rural helsetjeneste</li> <li>▪ PAS</li> </ul> <p>2 – datakilder, en for EMR – lokalt, fagspesifikt EPJ system og en for EHR (felles EPJ system på tvers av virksomheter og nivåer, lagrer informasjon i livsløp), med særskilt fokus på behov knyttet til datakildenes informasjonssikkerhet og standardisering.</p> <p>1 – dedikert nasjonalt helsenett linker de tre nivåene i plattformen sammen.</p> <p>Nasjonale planer spesifiserer ikke hvordan programmet skal realiseres, det er etablert flere piloter som utvikler regionale helseinformasjonssystemer basert på nasjonale retningslinjer. Enorme nasjonale forskjeller i utviklingsgrad. Beijing og Shanghai regnes som digitale spydspisser.</p>	
<p><b>Shanghai (Kina)</b></p> <p>23 millioner innbyggere</p>	<p>Offentlig, skatte- og egenandelfinansiert. Innflyttere er uten rettigheter. Spesialiserte og lokale sykehus tilbyr vestlig og tradisjonell kinesisk medisin. Primærhelsetjenestestasjoner etablert først på 80-tallet. Forsøker å innføre fastlegeordning (ingen portvokterfunksjon).</p> <p><b>Sentrale e-helse aktører</b></p> <p><u>Ministry of Health</u>: Publisere brede nasjonale (teknisk-funksjonalitet-innhold) standarder og igangsetter regionale pilot handlingsplaner basert på disse.</p> <p><u>District Health Bureau</u>: Ansvarlig for RHIN. Virksomheter velger fritt EPJ-system, så lenge de lar seg integrere med RHIN.</p>	<p>Shanghai har utviklet et Regional Health Information Network (RHIN). Ulike plattformer bestående av underliggende fagsystemer med semi-strukturert innhold er integrert med en webbasert samhandlingsportal. Data høstes daglig og lagres i felles regional database.</p> <ul style="list-style-type: none"> <li>• Integert <b>EPJ og PAS</b>.</li> <li>• Samhandlingsplattformen gir <b>tilgang til database med EPJ informasjon</b> fra lokale systemer.</li> <li>• <b>Telemedisin</b> kople primærhelsetjenesteseneter og egne team på sykehus slik at de sammen kan vurdere informasjon (lyd/bilde/tekst).</li> <li>• Pasientportal gir tilgang til egen helseinformasjon, samt informasjon om behandlere (ventetid, spesialiteter), prøvesvar, og eBooking.</li> <li>• <b>Selvmonitoreringskiosker</b> er etablert på helsesentrene og</li> </ul>	<p>Har nasjonale helse- og kvalitetsregistre.</p> <p>Data fra RHIN er sentral i styrings- og kvalitetsforbedringsarbeid på alle nivå og områder av helsetjenesten. Har blant annet utviklet et dashboard med KPIer og monitorerer status særlig på bruk av antibiotika, ventetid hos enkeltbehandlere og sykehusreinnleggelser.</p> <p>Det er utviklet noe prosess- og beslutningsstøtte for kronikere.</p>

		måler blodtrykk, vekt, mm. Data lagres automatisk i EPJ. Ved unormale prøver kalles pasienten inn til konsultasjon.	



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