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《電子健康紀錄互通系統條例草案》委員會主席

莫乃光議員

莫主席:

〈電子健康紀錄互通系統條例草案〉委員會第七次會議

本人在 2014 年 10 月 14 日《電子健康紀錄互通系統條例草案》委員會第七次會議上曾分 享外國電子健康的實施情況,並表示會把相關資料給予當局及委員會作為參閱。現致函附 上以下資料,煩請交予政府當局及各委員參考。

- 1. eHealth Strategies The Report for Denmark (European Commission 2010)
- 2. eHealth in Denmark (Danish Minstry of Health 2012)
- 3. MedCom for 20 years (MedCom 2014)
- 4. eHealth Strategies The Report for Finland (European Commission 2010)
- 5. eHealth Strategy and Action Plan of Finland in a European Context (Ministry of Social Affairs and Health, Finland 2013)
- 6. eHealth Strategies The Report for England (European Commission 2010)

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About eHealth Strategies and this report

The eHealth Strategies study analyses policy action and implementation progress of eHealth in EU and EEA Member States, with a special emphasis on barriers and enablers beyond technology. Progress with regard to specific applications such as patient summary and ePrescription is assessed. In addition, legal and regulatory facilitators and financing and reimbursement issues are also dealt with.

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Executive summary

The current Danish roadmap for eHealth is the "National Strategy for Digitalisation of the Danish Healthcare Service"¹ from 2008. The strategy's goal is to support the reorganisation of tasks and the adaptation of healthcare structures caused by digitalisation. Digitalisation is to be an integral element of all future healthcare initiatives. The implementation of the strategy is described in a number of specific action plans. Each action plan defines many different aspects, such as development, testing, implementation, application, operation, maintenance, monitoring and efficiency measurement.

Documents from other domains include the "Danish e-Government Strategy" from 2007. This strategy, which acted as the basis for the current eHealth plan, supports the digitalisation of the public sector in general.

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

The 2003 fiscal agreement between the government and county hospital owners resulted in the five new hospital regions adopting the standard of "one patient – one EHR" within each region. Furthermore, many Danish hospitals are carrying out development in relation to electronic patient records (EPR). To begin with there will be a shared EPR for each individual hospital, but this is also a basis for providing an interconnected EPR system for the entire hospital network and in the long term for the Danish healthcare services as a whole.

The National Patient Index (NPI) is Denmark's approach to the formation of a patient summary. The NPI is a "Health IT functionality, which allows an overview of existing health information (of given types) for a given patient / citizen from different and not necessarily otherwise integrated IT (source) systems". A fully integrated index will be in place by the end of 2013.

ePrescription has been widely adopted in Denmark: primary care providers routinely prescribe drugs electronically with ePrescribing and implementation rates at close to 100%. Primary care providers may issue a prescription either in writing, electronically, via telefax or via telephone. After successful implementation in Denmark, Computer Sciences Corporation (CSC) has said that they are prepared to provide their electronic prescription service across Europe.

An additional service for Danes is Apoteket.dk: a health portal created by the Pharmacy Association. This portal does not only provide information on drugs and personal health, but also allows patients to buy medicine online for delivery or pickup at their local pharmacy. In a special section on the website, pharmacists answer questions about the use of medicines.

¹ Connected Digital Health in Denmark 2007

Denmark



Standards, as developed by Danish healthcare organisation MedCom, are in widespread use in Denmark. The National Board of Health is Denmark's representative to the International Health Terminology Standards Development Organisation (IHTSDO).

In general, MedCom has been managing the national programme for telemedicine during the period 2008-2012. The programme's overall goal is to manage the problem of staff shortage through the use of telemedical services. This programme concentrates on the development of video conferences, home monitoring and image transfer techniques. The Danish Centre for Health Telematics is sponsoring the building of such telemedical infrastructure and has been integrated into MedCom.

Denmark has rolled-out two telehealth pilots using video conferencing, which are intended for national implementation over the next three years. Another telehealth pilot was also rolled-out at the beginning of September 2009 to monitor around 800.000 unstable chronic obstructive pulmonary disease patients from their home and a project for tele wounds has also been initiated.



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1 Introduction to the report

1.1 Motivation of the eHealth strategies study

Following the *Communication* of the European Commission (EC) on "eHealth – making healthcare better for European citizens: An action plan for a European eHealth Area".² Member States of the European Union (EU) have committed themselves to develop and issue national roadmaps – national strategies and plans for the deployment of eHealth applications addressing policy actions identified in the European eHealth Action Plan.

The 2004 eHealth Action Plan required the Commission to regularly monitor the state of the art in deployment of eHealth, the progress made in agreeing on and updating national eHealth Roadmaps, and to facilitate the exchange of good practices. Furthermore, in December 2006 the EU Competitiveness Council agreed to launch the *Lead Market Initiative*³ as a new policy approach aiming at the creation of markets with high economic and social value, in which European companies could develop a globally leading role. Following this impetus, the Roadmap for implementation of the "eHealth Task Force Lead Market Initiative" also identified better coordination and exchange of good practices in eHealth as a way to reduce market fragmentation and lack of interoperability.⁴

On the more specific aspects of electronic health record (EHR) systems, the recent *EC Recommendation on cross-border interoperability of electronic health record systems*⁵ notes under "Monitoring and Evaluation", that "in order to ensure monitoring and evaluation of cross-border interoperability of electronic health record systems, Member States should: consider the possibilities for setting up a monitoring observatory for interoperability of electronic health record systems in the Community to monitor, benchmark and assess progress on technical and semantic interoperability for successful implementation of electronic health record systems." The present study certainly is a contribution to monitoring the progress made in establishing national/regional EHR systems in Member States. It also provides analytical information and support to current efforts by the European Large Scale Pilot (LSP) on cross-border Patient Summary and ePrescription services, the epSOS - European patients Smart Open Services - project.⁶ With the involvement of almost all Member States, its goal is to define and implement a European wide standard for such applications at the interface between national health systems.

² European Commission 2004

³ European Commission 2007

⁴ European Communities 2007

⁵ European Commission 2008

⁶ European Patients Smart and Open Services (epSOS)



Earlier, in line with the requirement to "regularly monitor the state of the art in deployment of eHealth", the EC already funded a first project to map national eHealth strategies – the eHealth ERA "Towards the establishment of a European eHealth Research Area" (FP6 Coordination Action)⁷ - and a project on "Good eHealth: Study on the exchange of good practices in eHealth"⁸ mapping good practices in Europe - both of which provided valuable input to the present *eHealth Strategies* work and its reports. Member States' representatives and eHealth stakeholders, e.g. in the context of the *i2010 Subgroup on eHealth* and the annual European High Level eHealth Conferences have underlined the importance of this work and the need to maintain it updated to continue to benefit from it.

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

1.2 Survey methodology

After developing an overall conceptual approach and establishing a comprehensive analytical framework, national level information was collected through a long-standing Europe-wide network of national correspondents commanding an impressive experience in such work. In addition, a handbook containing definitions of key concepts was distributed among the correspondents to guarantee a certain consistency in reporting. For Denmark, the National Institute for Health and Welfare⁹ (THL) provided information on policy contexts and situations, policies and initiatives and examples for specific applications. THL generates information and know-how in the field of welfare and health and forwards them to decision-makers and other actors in the field. The centre is overseen by the Finnish Ministry of Social Affairs and Health.

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

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

⁷ eHealth Priorities and Strategies in European Countries 2007

⁸ European Commission; Information Society and Media Directorate-General 2009

⁹ National Institute for Health and Welfare (THL) 2010

F. Evaluation

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

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

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

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

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

1.3 Outline

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



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

The report finishes with a short outlook.

2 Healthcare system setting

2.1 Country introduction¹⁰

Politically and administratively, Denmark is organised in three levels: state, regions and Kommuner (municipalities). Since 2007, a structural reform consolidated the 15 "counties" (14 Counties plus Copenhagen region) into five "regions", and reduced the number of municipalities from 271 to 98, of which a large number have more than 30,000 inhabitants.

The purpose of the structural reform is strengthening and rationalising the work of the public sector. It leaves fewer responsibilities with the counties, and the power taken from the counties is then divided between the state level and the new, larger municipalities. This, however, does not alter the overall principle of government, namely that the public tasks which are close to the citizens' everyday life such as day-care, care for the elderly, schools and social support also are to be placed in the administrative level close to the citizen. Denmark has a strong tradition of delegating a number of important tasks to the municipalities at the local level.

Like Denmark as a whole, the healthcare sector has three political and administrative levels: the state, the regions and the municipalities (national, regional and local levels). The healthcare service is organised in such a way that responsibility for services provided lies with the lowest possible administrative level. Services can thus be provided as close to the users as possible. Put generally, the state level is responsible for the overall legal framework for healthcare and for the coordination and supervision of the services delivered on lower levels. The regions are responsible for primary and secondary care and the municipalities are responsible for different types of care which are not related to hospital inpatient care including e.g. prevention and rehabilitation.

¹⁰ eUser 2005



The box below summarises the key facts about the Danish healthcare system:

Key facts about the Danish healthcare system:¹¹

Life expectancy at birth: 78.1 years

Healthcare Expenditure as % of GDP: 9.8% (OECD 2007)

WHO Ranking of Healthcare systems: rank 25

Public sector healthcare expenditure as % of total healthcare expenditure: 85% (OECD 2007)

2.2 Healthcare governance

Decision making bodies, responsibilities, sharing of power

The Ministry of the Interior and Health is responsible for health policy, guidelines and legislation, including legislation on healthcare provision, personnel, hospitals, pharmacies, pharmaceuticals, vaccinations, maternal healthcare, child healthcare and patients' rights. Furthermore it is in charge of the administrative functions in relation to the organisation and financing of the healthcare system, psychiatry and health insurance as well as the approval of pharmaceuticals and the pharmacy sector. Prevention and health promotion are also part of the Ministry's remit.

The task of the state in healthcare provision is first and foremost to initiate, coordinate and advise. One of the main tasks is to establish the goals for a national health policy. The Ministry of the Interior and Health in its capacity of principal health authority is responsible for legislation on healthcare. This includes legislation on health provisions, personnel, hospitals and pharmacies, medicinal products, vaccinations, pregnancy healthcare, child healthcare and patients' rights.

The Ministry of the Interior and Health's legislation covers the tasks of the regions and the municipalities in the health area. The Ministry also sets up guidelines for the running of the healthcare service. This is mostly done through the National Board of Health. Moreover, the Ministry of the Interior and Health supports efforts to improve productivity and efficiency by e.g. the dissemination of experience and the professional exchange of information and by the introduction of economic incentives and activity based payment.¹²

As the running of hospitals requires a larger population than that of the majority of the municipalities, this responsibility lies with the five regions. The regions are also responsible for the practice sector. The regions organise the health service for their citizens according to regional wishes and available facilities. Thus, the individual

¹¹ Data from World Health Organization 2000; Health Consumer Powerhouse 2008; World Health Organization 2009

¹² Ministry of Health and Prevention 2010



regions can adjust services within the financial and national legal limits according to needs at the different levels, enabling them to ensure the appropriate number of staff and procurement of the appropriate equipment.

The 98 municipalities are local administrative bodies. The municipalities have a number of tasks, of which health represents one part. In the health field, the municipalities are responsible for home nursing, public healthcare, school health service, child dental treatment, prevention and rehabilitation. The municipalities are also responsible for a majority of the social services, some of which (subsidised housing for older people in the form of non-profit housing, including homes for elderly people with care facilities and associated care staff) have to do with the healthcare service and they are of great importance to the functioning of this service.

Healthcare service providers¹³

Primary healthcare is provided by self-employed healthcare professionals and municipal health services. General practitioners play a key role in the Danish healthcare system as gatekeepers to specialists, physiotherapists and hospitals. Since the free choice of hospital system was introduced in 1993, general practitioners also fulfil an important function in advising patients on which hospital to choose. General practitioners operate private practices, either on their own (about a third) or in collaboration with other general practitioners. As a result of collaboration between different practices, general practitioners' services are available 24 hours a day.

General practitioners are paid on a combined capitation and fee-for-service basis. The counties control the number and location of general practitioners, and their fees and working conditions are negotiated centrally. Visits to a GP are free for 98% of the population who chose the insurance option 1 which enables them to consult any GP of their choice for free, if they accept to see specialists they can do so with a referral by the GP.

The majority of hospitals in Denmark are owned and financed by the counties. Exceptions to this are private for-profit hospitals (<1% of total beds). Since 1993, many counties have introduced "soft" contracts for hospitals, which supplement the global budget and are intended to raise awareness of costs and increase activity by setting targets for activity, service and quality. A related trend has been to delegate management and financial responsibility to even lower levels, such as hospital departments, in order to create greater awareness of costs and stronger economic incentives at the point of delivery.

Political and media interest in the issue of waiting lists for hospital treatments during the 1990s resulted in the allocation of additional funds to the counties and the declaration of maximum allowable waiting times for specific treatments. In June 2002

¹³ Strandberg-Larsen, Nielsen et al. 2007; Ministry of Health and Prevention 2010



patients were guaranteed access to treatment within two months, a delay that had been reduced to one month by 2007. If public hospitals are unable to offer treatment after this maximum delay has elapsed, patients have the right to refer themselves to private hospitals or hospitals abroad.

The hospital sector deals with medical conditions which require more specialised treatment, equipment and intensive care. In addition to the treatment of patients, both general practitioners and hospitals are involved in preventive treatment as well as in the training of health personnel and medical research.

Some public health services are integrated with curative services, while others are organised as separate activities provided by specialist institutions. Responsibility for the surveillance and control of communicable diseases lies with public health officers. General vaccination programmes are carried out by general practitioners and funded by the counties on a fee-for-service basis. Children have access to free health examinations. Pregnant women have access to free ante-natal services provided by general practitioners, midwives and obstetricians in hospital obstetric departments.

Political/administrative unit responsible for primary healthcare	GPs and other private practitioners at the regional level, other services on the municipal level.
Consumer Choice	Free choice of GP within a list patient system; restricted number of GP changes per year.
Financing	Mainly tax-based financing.
Public or private providers	GPs in private practices; otherwise mainly publicly employed primary care providers.
Gatekeeping function of the GP	Patient access to specialists, physiotherapists, hospitals and some other services regulated by GP referrals.
Integrating health: initiatives for coordination	Individual patient plans; practice coordinators; regional health plans jointly with municipalities.

Figure 1: Important features of primary healthcare organisation in Denmark¹⁴

¹⁴ Krasnik and Paulsen 2009



2.3 Recent reforms and priorities of health system/public health

Currently ongoing reforms in the health and social care systems

A major structural reform of the administrative system was passed by the Danish Parliament in 2005. The reform was implemented in 2007, with 2006 as a transition year. The reform reduced the number of regional authorities from 14 counties to 5 regions (0.6–1.6 million inhabitants per region) and the number of municipalities from 275 to 98 (37% of the new municipalities have more than 50 000 inhabitants; 38% have 30.000–50.000; 18% have 20.000–30.000; and 7% have fewer than 20.000 inhabitants). Both levels are governed directly by elected politicians. The main responsibility of the regions is to provide specialist healthcare services, but some environmental and regional development tasks have also been maintained at this level. Most other tasks have been moved to either the State or the municipalities. The new municipalities have assumed full responsibility for prevention, health promotion and rehabilitation outside of hospitals.

From an economic point of view, several important changes have been implemented. First, the regions' right to tax was removed. Healthcare is now financed by a combination of national earmarked "health taxes" (the new state health contribution), which are redistributed in terms of block grants to regions and municipalities. A total of 80% of the regional healthcare activities are financed by the State via block grants and some activity-based payments (approximately 5%). The remaining public financing for regional healthcare activities comes from municipal contributions, which are paid as a combination of per capita contributions and activity-based payments related to the use of services by the citizens of the municipality.

The idea behind the municipal co-financing is to create incentives for municipalities to increase preventative services in order to reduce hospitalisation. The impetus behind the new state health contribution is to create greater transparency for taxpayers with regards to their health contributions and priorities. The size of the block grants from the State are calculated according to a formula, which includes the expected healthcare needs of the population as a central component. The expected need is assessed by combining the number of inhabitants in different age groups and across certain socioeconomic status levels.¹⁵

¹⁵ Strandberg-Larsen, Nielsen, Krasnik & Vrangbaek 2006



Denmark

2.4 eHealth setting in the country

This section provides a brief overview of relevant ICT related infrastructure and services data. It draws on earlier studies commissioned by the EC, notably the Indicators eHealth Study . Although the results of this study date from 2007 and may therefore not reflect latest changes, a more recent pan-European survey is not available¹⁶.

In terms of infrastructure, 99% of the Danish GP practices use a computer. The same share of practices disposes of an Internet connection. In Denmark, broadband represents the usual form of access to the Internet with 91% of GP practices resorting to broadband connections.

With regard to the availability of a computer in the consultation room as compared to the actual use of the PC in consultations with the patients, there is nearly no gap as both availability and use are nearly universal (98% of practices and 92% of practices respectively).

Local Electronic Health Records are common practice in Denmark. Medical patient data is stored in digital form in more than 90% of GP practices. Especially remarkable is the high share of stored radiological data which in Denmark is the reality in 98% of the GP practices.

In Denmark the use of electronic networks for the trans-mission of medical patient data is well established and widespread. 96% of GP practices receive analytic results from labs and 74% exchange data with other healthcare providers. As far as ePrescribing is concerned, ePrescriptions are extensively used. Also with regard to this point, 97% of GP practices reported the regular utilisation of ePrescribing.

Denmark's history of dedicated eHealth strategies ranges back to 1996. The development of Electronic Patient Records (EHR) in particular was already launched in 1996. Later on, the eHealth strategy of 2003 provided for the comprehensive implementation and the further upgrading of EHRs. Plans were made for the extension of the ePrescribing system to arrive at a personal medication profile stored on a national prescription server and 29 individual initiatives in the eHealth domain were agreed on.

¹⁶ ICT and eHealth use among General Practitioners in Europe 2007





Figure 2¹⁷: eHealth use by GPs in Denmark

3 eHealth strategies survey results

The following sections present the results of the eHealth strategies country survey. In a first section, the eHealth policy actions undertaken in Denmark are presented. This is followed by a presentation of administrative and organisational measures taken. Section 3.2 presents results on key eHealth applications. Section 3.3 focuses on the technical side of eHealth, namely the role of patient and healthcare provider identifiers and the role of eCards. Legal and regulatory facilitators as well as financing and reimbursement issues are presented in the following chapters, 3.4 and 3.5. The report concludes with evaluation activities (3.6) in the country and an outlook (4.).

3.1 eHealth policy action

The eHealth strategies of EU and EEA countries are not always labelled as such. Some countries may indeed publish a policy document which refers to the ICT strategy in the healthcare sector. Countries such as France and Germany for

¹⁷ The notion of "compound indicator" designates an indicator built from a set of other indicators/survey questions regarding the same topic. The compound indicator reflects an average calculated from different values. (see Annex 6.1.1) The final results of the study on eHealth Indicators is available at <u>www.ehealth-indicators.eu</u>.

Denmark



example have enshrined the central eHealth activities in legislation governing the healthcare sector. In Germany, the relevant law is the law on the modernisation of healthcare; in France the introduction of an electronic medical record is included in a law concerning social security.

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

3.1.1 Current strategy/roadmap¹⁸

The current Danish roadmap for eHealth is the "National Strategy for Digitalisation of the Danish Healthcare Service"¹⁹ from 2008. It was developed by the organisation "Connected Digital Health in Denmark" The strategy is connected to four programmes, which govern a number of projects and are realised in different specific action plans. As Denmark already has a history of eHealth strategies, this policy paper is the fourth one, which is concerned with governance of digitalisation in healthcare.

The strategy has the goal of supporting the reorganisation of tasks and the adaptation of healthcare structures. Digitalisation is therefore said to be an integral element of all future healthcare initiatives, including e.g. the organisation of health services, the expansion and modernisation of hospitals, equipment and infrastructures.

Specific goals that the strategy addresses are:

- Digitalisation, as a tool for the employee to create quality and productivity;
- Better service and inclusion of citizens and patients;
- Stronger cooperation to create digital connectivity.

The implementation of the strategy is described in a number of specific action plans. These plans address issues, objectives and projects within limited areas in the period from 2008 to 2012. Each action plan defines many different aspects, such as development, testing, implementation, application, operation, maintenance, monitoring and efficiency measurement. At present, four different plans are encompassed by the digitalisation strategy in Denmark:

Digitalisation of the Danish Healthcare Service 2008-2012

National Strategy for

¹⁸ Connected Digital Health in Denmark 2007; Sammenhængende Digital Sundhed i Danmark 2008; Ministry of Health and Prevention 2010

¹⁹ Connected Digital Health in Denmark 2007



Action Plans connected currently to the digitalisation strategy:

Action Plan 1: describes the projects aimed at establishing staff tools for supporting healthcare quality and productivity.

Action Plan 2: describes projects aimed at improving services and involving citizens and patients.

Action Plan 3: describes the projects aimed at establishing a common infrastructure.

Action Plan 4: describes projects aimed at local digitalisation.

Thereby, the Danish national strategy represents a stable overall governing tool. This means that it does not operate with a fixed number of initiatives to be carried out during the strategy period, but supports implementation by various dynamic action plans, which again consist of different programmes and projects. In sum, the strategy builds on incremental digitalisation of the whole health sector.

As already mentioned, this is already the fourth Danish strategy for eHealth, following earlier documents from 1996, 2000 and 2003. The specific goals of the strategies have been different, but throughout this time, the core element remained the same - the goal of being valuable to patients and professionals in the healthcare sector. The present strategy is based on the following previous policy papers:

Previous Danish policy papers for eHealth:

- (1) Danish Action plan for EHR (1996)
- (2) National Strategy for IT in the Danish Hospital System²⁰ (2000-2002)
- (3) National IT strategy for the Danish Health Care Service²¹ (2003-2007)

The first plan from 1996 was developed on the basis of several user group analyses made in cooperation with healthcare professionals, IT-vendors and health informatics specialists. It consisted of several recommendations and led to the financing of EHR-projects, addressing topics such as standards, security, organisation, implementation and information. The responsibility for carrying out the action plan was rather decentralised and resulted in a slow and distributed approach. Based on the experiences of the first action plan, the Ministry of Health stated in 1999 the need for a coordinated development, focusing on key elements in the healthcare sector. Consequently the "National Strategy for IT in the Hospital Sector 2000-2002" was developed.²²

The objective of this strategy was to point out the necessary initiatives for the hospital IT systems, in order to support the work and realisation of the political

²⁰ National Board of Health 2003

²¹ The Ministry of the Interior and Health 2003

²² Lippert and Kverneland 2003



healthcare goals, which were: high health professional quality, clear information and short waiting times, high user acceptance, better information regarding service and quality and efficient use of resources.

The National IT Strategy for the Danish Health Care System 2003-2007 had the core principle of creating shared information as the foundation for seamless care and patient involvement.

Denmark was part of the "Baltic eHealth" and the "eHealth for Regions project" Documents from other domains include the "Danish e-Government Strategy" from 2007. This strategy, which acted as the basis for the current eHealth plan, supports the digitalisation of the public sector in general, in the form of more cohesive and efficient digital services to citizens and businesses.

On the regional level, Denmark participated in the "Baltic eHealth" ²³and the "eHealth for Regions" ²⁴projects. Here, the network members worked together in transnational projects, including organisations from Sweden, Finland, Germany, Lithuania and Poland. For Denmark, the "Danish Regions" and the "North Denmark Region" took part, aiming to establish a network for healthcare data and integrated eHealth structures.

The "Integrated eHealth Structures in the Baltic Sea Area" Project was a cooperation from June 2004 until 2007 in the main fields of eCardiology, eRadiology, Exchange of patient information and Ferries with Tele ECG at the Baltic Sea. The other project, "Baltic eHealth", aimed – between 2004 and 2007 – to establish a Baltic Healthcare Network by connecting existing national and regional healthcare data networks in the participating countries and carrying out full-scale eHealth trials within the fields of radiology and ultrasound.

²³ Baltic eHealth

²⁴ eHealth for Regions

Denmark

eHealth

Figure 3: Danish policy documents related to eHealth



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Administrative and organisational structure²⁵

Cross-governmental organisation "Connected Digital Health in Denmark" In Denmark, the main organisation responsible for eHealth procurement as well as strategy and specification of infrastructure has been reformed in 2010. To ensure efficient development efforts are made to ensure collaboration across sectors, but also to ensure that responsibilities are uniquely defined. Institutions, which are important for the day-to-day running of the infrastructure, are: 1) the eHealth Portal "Sundhed.dk"²⁶ and 2) the non-profit cooperative venture "MedCom"²⁷.

In the summer of 2010 the work on eHealth was reorganised.

The Ministry of the Interior and Health and its various agencies remain the authority in decision-making in relation to e.g. national standards and national infrastructure. . Regions and municipalities are in charge of managing their own projects and observing the framework and requirements laid down at the national level. Consequently, the regions and municipalities are essential to the successful implementation of the strategy. It is therefore necessary to ensure a professional and well-structured effort at the local level.

²⁵ Connected Digital Health in Denmark 2007; Danish eHealth portal 2008; Ministry of Health and Prevention 2010

²⁶ Sundhed.dk

²⁷ Medcom

Denmark



The Ministry has assumed responsibility for the overall coordination of e-health. To that end an advisory board is to be established in the autumn of 2010 with representatives from government, regions and municipalities. Under the auspices of the Ministry activities concerning cross sectorial communication are being dealt with (standards, architecture etc.).

On the more operational level the regions has established an organisation aiming at setting goals for the digitalisation of primarily the hospitals. Activities are initiated on the basis of the national strategy for digitalisation of the healthcare service 2008-2012. Focus is on ensuring increased collaboration i.e. by efficient investment in eHealth on the basis of shared procurement, shared operations and shared solutions.

The Danish eHealth portal "Sundhed.dk" The other two institutions mentioned above, Sundhed.dk and MedCom, also operate at a national level and are part of the public eHealth infrastructure. These organisations are providing solutions in well defined areas.

Sundhed.dk is an eHealth portal established between all public health authorities in Denmark. The portal was launched in 2003, and is part of the common infrastructure in the healthcare sector in Denmark. It is the official Danish eHealth portal for the public healthcare services and can be accessed with a digital signature – distinguishing between citizens and professionals. Citizens can gain access to general and personal information and professionals have access to a number of services including reading electronic records etc. under the ruling of the Danish Data Protection authorities. Regarding stakeholder involvement, the portal is run by a political board with members from Danish regions, the Ministry of Health, the Association of Municipalities and the Association of Pharmacies.

The other institution operating at the national level is MedCom. This non-profit cooperation between authorities, healthcare professionals and private firms was established in 1994 to primarily serve the needs of GPs. Generally speaking, it is a national project organisation, involved in the development, testing, distribution and quality assurance of the electronic communication and information in the healthcare sector. Thereby, it focuses on the following fields: 1) project implementation and 2) communication standards and health data networks. MedCom is financed through the Ministry of Health and Prevention, the Ministry of Social Welfare, the Danish National Board of Health, the Danish Regions, by the Local Governments and the Danish Pharmaceutical Association. As an extension, MeCom International²⁸ was established in January 2007, in order to carry on the active role of MedCom in international eHealth collaboration.

As a consequence of the reorganising SDSD will be closed by the end of 2010. The Ministry of the Interior and Health has as a consequence of this assumed a more direct responsibility of a number of the tasks previously handled by SDSD i.e.

The non-profit cooperative venture "MedCom" and "MedCom International"

²⁸ MedCom International

Danish National

Patient Registry (DNRP) collecting

data since 1977



national governance and coordination of activities as well as the carrying out of prioritised projects. The reason for this is a desire of at stronger national governance.

3.2 Deployment of eHealth applications

3.2.1 Patient summary and electronic health record (EHR)²⁹

In this study, the epSOS project's definition³⁰ of a patient summary was used as a general guideline. There a patient summary is defined as a minimum set of a patient's data which would provide a health professional with essential information needed in case of unexpected or unscheduled care (e.g. emergency, accident), but also in case of planned care (e.g. after a relocation, cross-organisational care path).

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

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

Denmark has a common infrastructure in the form of the National Patient Registry (DNRP), which has served as a data set of hospital contacts since 1977. This is a unique registry featuring long-term comprehensive documentation, on the level of the individual. It has been collecting discharge diagnoses, surgical codes and recently also different diagnostic and treatment codes from all Danish hospitals in accordance with the current legislative framework. Besides being an administrative tool and a tool for epidemiological research through recent years, the DNRP has also supported national clinical quality databases.

²⁹ The Ministry of the Interior and Health 2003; Connected Digital Health in Denmark 2007; European Commission 2007; Castro 2009; Lidegaard, Vestergaard et al. 2009

³⁰ European Patients Smart and Open Services (epSOS)



With regard to current developments, it can be stated that Denmark benefited from this common infrastructure established in relation to the National Patient Registry: a number of shared services have been or are being established. These include the National Patient Index providing access to all relevant information about individual patients.

The National Patient Index (NPI) is Denmark's approach to the creation of a patient summary and the answer to the problem of inadequate access and overview of patient data. The NPI is a "Health IT functionality, which allows an overview of existing health information (of given types) for a given patient / citizen from different and not necessarily otherwise integrated IT (source) systems". ³¹ The vision for the National Patient Index (NPI) is to provide patients and healthcare professionals in Denmark access to relevant patient data at the right time and right place. By establishing the patient reference list or index, the sharing of patient data across countries, regions and sectors will become possible. In turn, appropriate availability of patient data could allow for greater patient safety, improved treatment quality and more efficient workflow. In addition, patients will be guaranteed the possibility of a more active involvement in their own treatment.

The index will in the outset be based on existing data sources, and will be supplemented with new relevant sources continuously. An index fully integrated to the clinical workstation shall be in place at the end of 2013. This index will also be made available to citizens through sundhed.dk..The service called "My Health summary"³² is available through the Danish eHealth portal 'Sundhed.dk' for citizens and allows authenticated users to obtain a faster and better overview of their own patient data.³³

Once logged into the health portal with their digital signature, users can access personal health information that has been gathered from various healthcare sources. The available data includes:

- Summary of hospital admissions (back to 1995);
- Recent notes from hospital charts;
- Summary of medication prescribed over the last two years;
- Overview of personal wishes in relation to organ donation and receiving lifeprolonging treatment (living wills);
- Status of laboratory tests ordered by physicians;
- Contact information for the personal General Practitioner (GP).
- "My Health summary" will be replaced by the above-mentioned patient index. With the index it will be possible to integrate and access information directly into for example the HER or the EMR.

³¹ Clausen and Bruun-Rasmussen 2009

³² Ministeriet for Sundhed og Forebyggelse [Department of Health and Prevention]

³³ ePractice.eu 18/3/2010

Mature data collecting and communication systems at a local level Sundhed.dk and MedCom (see 0) – general and individual health information. The eHealth portal Sundhed.dk allows Danish citizens and healthcare professionals to access this kind of information and communicate with each other. Another component of the national health infrastructure is the Danish Health Data Network managed by MedCom, which enables healthcare organisations to securely exchange health data.

Denmark's common national IT infrastructure also provides - through the service of

Most of the data sets and communication structures are in place at a local level in a mature way. But eHealth sector stakeholders are aiming for shared services with consistency in and access to data at a national level. A number of specific shared services are being developed, making data and/or functionality available via Sundhed.dk or via the integration with local solutions of the individual players, which are then made available to users (e.g. via integration with EPR³⁴, ECR³⁵ or practice systems).

The local storage of patient data is extremely commonplace, and not limited to administrative data: It is related to medications, lab results, radiological images, information on symptoms and medical history, as well as data on treatment outcomes, basic medical parameters and examination results. In addition to local data storage, different IT systems are used within healthcare services. Some of these systems are combined to what is known as the electronic health record, including e.g. IT systems giving access to notes, medicine data, treatment plans and results of examinations, planning and booking of examinations and support for clinical decisions. According to an external EPR review performed in 2007³⁶, there are 23 EPR landscapes (17 in 2010 and a goal of having 5 by the end of 2013) (each linking a number of systems), 13 practice systems and 4 electronic care record (ECR) systems.

As the integration of the different systems in Denmark is required and could be an advantage for areas where technologies are relatively mature, common guidelines and agreements are in the process of development. The Ministry of Health for example launched its first strategy for the development of electronic patient records in 1996 when through a number of decentralised, regional pilots the need for standards and common terminology was identified (see section 3.1.1). The 2003 fiscal agreement between the government and the county hospital owners required that electronic health records based on shared standards being implemented in all Danish hospitals by the end of 2005. The five new hospital regions have adopted the principle of "one patient – one EHR" within each region.



different systems to create EHR

Goal of integrating

³⁴ Electronic Patient Record

³⁵ Electronic Cash Register

³⁶ Deloitte 2007



Furthermore, many Danish hospitals are carrying out extensive development work in relation to electronic patient records (EPR). The vision is that these records will replace paper records in the not too distant future and will in fact become the definitive main source for all relevant patient information. Initially, the idea is to have a shared EPR for each individual hospital, but this is also a natural basis for providing an interconnected EPR system for the entire hospital network and in the longer term for the Danish healthcare services as a whole.

Another example for making local systems consistent is the "Personal Medicine Profile": The Personal Medicine Profile is a register which provides the patients and the healthcare professionals, via Sundhed.dk, with an electronic overview of the individual patient's consumption of prescribed medicines. Registration is mandatory and automatically, but the goal is to integrate the Medicine Profile with local solutions. This has to optimise the use of medication, for example at hospitals, by GPs or at old people's homes.

The following are examples of existing or future solutions that could be developed towards shared services:

Examples of existing/future shared services:

<u>E-journal</u>: makes information from hospital PAS and EPR systems available to GPs and the citizens themselves.

<u>Shared medicine record</u>: makes updated information about the current medicine consumption of the individual patient available to relevant staff at hospitals, GPs, old people's homes, etc.

<u>Decision-making support for clinicians</u>: makes clinicians aware of previously registered allergy to drugs for a certain patient or warns of interaction between different drugs.

<u>National patient index</u>: provides an overview of healthcare data about each patient.

<u>Course of treatment service</u>: provides information about recommended courses of treatment for given diagnoses. Clinicians can use this information to plan the individual patient's journey through the healthcare service.

<u>Text reminder service</u>: can be used by individual healthcare players to send reminders to patients before examinations, etc.

In sum, work is underway to further interact between established local systems e.g. by linking hospital medication systems to the personal electronic personal medical profile.

Cardiac summary in place, Diabetes management system under development

Regarding condition-specific summaries, Denmark has a cardiac summary where every patient has a custom-made webpage with information relevant to his or her own medical history. Additionally, patients have the possibility to participate in a



diabetes management system that allows them to better understand their medical history, treatment options and self-care regimen.

Challenges mostly occur in relation to the introduction of IT systems that could replace traditional hardcopy records as well as IT booking systems for planning work at hospital departments. This is to a large extent due to the absence of standard IT systems in these areas. It is pointed out that the use of a single national EPR system by all hospitals would mean launching a national project of considerable size, complexity and duration. In this perspective, it is suggested to lay down a number of requirements for regional consolidation, based on common architectural principles, so that regional consolidation will to some extent prepare the regions for a more coherent national technical infrastructure.

Figure 4: Patient summary in Denmark



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3.2.2 ePrescription

Denmark as leading country in ePrescription

In the framework of this study and following work in epSOS³⁷, ePrescription is understood as the process of the electronic transfer of a prescription by a healthcare provider to a pharmacy for retrieval of the drug by the patient. In this strict sense, only few European countries can claim to have implemented a fully operational ePrescription service.

At the moment, Denmark is one of the leading countries in ePrescribing, as primary care providers routinely prescribe drugs electronically with ePrescribing adoption rates at nearly 100%. This high rate of ePrescriptions is related to the action taken by the national government, as ePrescribing is made possible for primary care

³⁷ European Patients Smart and Open Services (epSOS)



providers which may issue a Prescription either in writing, electronically, via telefax or via telephone. In addition, primary care providers can issue all patient referrals to specialists electronically and maintain electronic clinical records using MedCom standards. As of 2009, the providers also offer online booking and e-mail consultations.³⁸

Central Prescription Server and Medicine Profile in place

The Danish architecture for ePrescribing includes a Prescription Server and the Medicine Profile, which have been established in recent years.

The Medicine Profile is an electronic overview of the purchase of prescription medication in Denmark. All purchases are automatically registered and gathered in an individual, personal medical profile for every citizen. This is achieved by substituting earlier EDI-based prescription messaging by XML -messages sent directly to the National Health Portal. The Medicine Profile project aims to improve quality of drug therapy, while giving a valuable overview of patient compliance.³⁹ The next step related to the Medical Profile is to complement it with medications from hospital treatment in order to complete medication information. The aim is to integrate the Profile with local solutions and to optimise the use of medication, for example at hospitals, by GPs or at old people's homes.⁴⁰

In 2007, the Danish Medicines Agency launched a central prescription server which can send prescriptions electronically from doctors to pharmacies. Since its launch the server has repeatedly been down, stopped the sending of prescriptions or worked slowly. To resolve these problems, the Association of Danish Pharmacies put pressure on the authorities.⁴¹

Additionally, Apoteket.dk as a health portal for Danes has been created by the Pharmacy Association. This portal does not only provide information on drugs and personal health, but also allows patients to buy medicine online for delivery or pickup at their local pharmacy. In a special section on the website, pharmacists answer questions about the use of medicines. Every week, more than 28,000 Danes visit the portal. To ensure the security of the system, customers must use the digital signature, provided by the national government, when purchasing medicines electronically. Pharmacies can also offer online consultation for their customers through online chat, webcams or e-Mail.⁴²

In cooperation with the Danish Medicines Agency, the Pharmacy Association also launched "Medicinkombination.dk"⁴³, which is a website for anyone who uses more than one kind of medicine, medicinal herbs, potent vitamins or minerals. In a simple

"Apoteket.dk" and "Medicinkombination. dk" as eHealth portals for drugs and drug interaction information

³⁸ Juhl 2006; Castro 2009; MedCom Statistics 2009; Protti, Johansen et al. 2009

³⁹ European Commission 2007; Ministry of Health and Prevention 2010

⁴⁰ Connected Digital Health in Denmark 2007; Ministry of Health and Prevention 2010

⁴¹ The Association of Danish Pharmacies 2008

⁴² The Association of Danish Pharmacies 2008; Castro 2009

⁴³ The website won the World Summit Award in the category eHealth in 2007.



language the user receives clear information about what to do if there is a risk for interaction. The database is part of the new eTrade solution at "Apoteket.dk".⁴⁴

Furthermore, Computer Sciences Corporation (CSC) has said that they are prepared to provide their electronic prescription service across Europe after successful implementation in Denmark. The system is based on CSC's Opus Medication solutions and Home Care Solution, CSC VITAE suite, which interfaces with a national repository of prescriptions developed by the Danish National Board of Health⁴⁵.

Figure 5: ePrescription progress in Denmark



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3.2.3 Standards

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

Standards – mainly for message-based communications – are in widespread use in Denmark. Responsible for the development and deployment of these standards is the Danish healthcare organisation MedCom, which sets standards for IT systems, acts as a coordinating body to bring together healthcare providers, laboratories,

⁴⁴ The Association of Danish Pharmacies 2008

⁴⁵ Sarah Bruce: E-Health-Media Limited 2010



vendors and others in order to develop interoperable standards. Denmark's representative to the International Health Terminology Standards Development Organisation (IHTSDO) is the National Board of Health.

The digitalisation strategy for the public sector foresees that standards should in general be based upon international, market-driven common public standards. In order to ensure gradual development and prioritisation of these areas, where the need is the greatest, future work is aiming towards "inside-out" standardisation, which means focusing on limited areas and gradually extending the standards from there. This is said to be done in sufficient interaction with the "outside-in" standardisation principle, which entails the standardisation of the overall framework, followed by a specification development for individual areas.

Relevant international standards exist in a number of areas in Denmark, for example classifications and terminologies such as ICD10, ICPC and Snomed CT. There are also relevant standards for laboratory data and imaging (X-rays, etc.), for example the DICOM standard. Internationally, technical standardisation is performed by, for example, the standardisation organisations ISO (global), HL7 (US) and CEN (European). MedCom's standards for communication of messages are based on CEN standards and are in widespread use in Denmark.⁴⁶

3.2.4 Telemedicine

The use of telemedicine applications is recognised as beneficial to enable access to care from a distance and to reduce the number of GP visits or even inpatient admissions. Commission services define telemedicine as "the delivery of healthcare services through the use of Information and Communication Technologies (ICT) in a situation where the actors are not at the same location"⁴⁷. In its recent communication on telemedicine for the benefit of patients, healthcare systems and society, the Commission re-emphasises the value of this technology for health system efficiency and the improvement of healthcare delivery⁴⁸.

Telemedicine has raised increased attention in Denmark, especially connected to tele-homecare, which is important for patients who need constant contact to healthcare services because of long-term or chronic illnesses or because they live in rural areas. In general, MedCom manages the national programme for increased use of telemedicine during the eHealth strategy period between 2008 and 2012. The program has the overall goal of dealing with the shortage of staff through the use of telemedical services, without loss in the quality of provided care. This programme

⁴⁶ International Health Terminology Standards Development Organisation; Connected Digital Health in Denmark 2007

⁴⁷ Europe's Information Society 2009

⁴⁸ European Commission 2008

Pilots on

patients

communication

chronic disease

between healthcare professionals and

Denmark



concentrates on the development of video conferences, home monitoring and image transfer techniques.

The Danish Centre for Health Telematics, which has been integrated into MedCom, has furthermore sponsored multiple programmes to build a useful telemedicine infrastructure.

Examples of National Programmes by the Centre for Health Telematics are listed below:

National programmes by the Centre for Health Telematics:

- Tele-dermatology project
- Tele-alcohol and -abuse rehabilitation programme
- Teleradiology programme
- Tele interpretation
- Tele wounds
- Cross-border telemedicine (Baltic eHealth project)

New forms of telemedicine solutions are continually developed in different pilot projects with the focus on two major areas: 1) Communication between healthcare professionals; 2) Tele-homecare.

For the communication between healthcare professionals, the focus has been on video conferences and specialist consultation during the video transmission of operations. Telemedicine is also used to transfer results between hospitals, such as X-rays and mammogram screening diagnosis. Related to this, Denmark has rolled-out two telehealth pilots, which are intended for national implementation over the next three years. One of the projects, already rolled-out at the Odense University Hospital, involves using a video conferencing service to allow foreign patients who do not speak Danish to communicate with hospital staff. The service uses a video conferencing system, linked to a call centre with multi-lingual operators, who can translate a person's needs or problems immediately to help them receive a better diagnosis. The first interpretation centre was opened at the beginning of June 2009. Regional implementation of the system is expected by 2010, with a national roll-out to be completed by 2012.

A telehealth pilot was also rolled-out at the beginning of September 2009 to monitor around 800.000 unstable chronic obstructive pulmonary disease patients from their home. Hereby, patients receive a package of video conferencing equipment and monitoring devices and the nurses do their normal rounds over a video conference system where they record the patients' vital signs. The solution is expected to be rolled-out nationally from 2012.⁴⁹

⁴⁹ Danish eHealth portal 2008; Bruce 2009



Finally a project concerning tele wounds has been initiated. This project provides functionality making it possible for an expert to interpret a picture of a wound e.g. taken by the home nurse and on the basis of this picture instruct the nurse in the correct care of the wound. This way it gets possible to use specialised competences in a cost efficient manner.

The Danish National Board of Health has also issued legal guidelines regarding the use of telemedical services, which are further explained in section 3.4.



Figure 6: Telemedicine services in Denmark

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3.3 Technical aspects of implementation

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

3.3.1 Unique identification of patients

Since 1968, every Danish citizen receives at birth a personal identification number called "CPR" (Centrale Personregister). It is a ten-digit code of which the first six digits indicate the date of birth, while the last four digits are a serial number. The last



digit (control digit) shows the person's gender by giving women an even number and men an odd number. The CPR-number is registered in the central National Register. In that register comprehensive information about the citizens is stored, including information about the name, address, birth registration, citizenship, marital states, kinship and relations to the national church. It does however not contain any medical information. The number is mandatory to all persons born in Denmark and persons with a residence permit receive a personal identification number in connection with their permit⁵⁰. The CPR-Office is the Danish government agency that houses the central registration system.

The CPR-number is used as identifier in all parts of the public sector, as well as the finance sector. In the healthcare sector the CPR-number is used for identification of the patient, both by public and private healthcare providers. The number must furthermore also be included in all patient records⁵¹.

The CPR-number is however not incorporated in an identity card. As an identifier the in 2007 introduced Health Card is used. The Health Card substitutes the social security card and contains the patient's CPR-number, name and address, name of his doctor, social security category and municipality. Apart from being an identifier – used not only in healthcare – the card also gives access to healthcare free of charge.

3.3.2 Unique identification of healthcare professionals

In Denmark, the following professions must hold an authorisation to be able to use their professional title:

Professions, which need an authorisation number:

Chiropodist, chiropractor, clinical dental technician, clinical dietician, dental hygienist, dentist, medical doctor, medical laboratory technologist, midwife, nurse, occupational therapist, optometrist or contact lens optometrist, physiotherapist, prosthetics and orthotist, radiographer and social and healthcare assistants.

Those professionals are registered in a central national register which is available online and which is maintained by the National Board of Health (Sundhedsstyrelsen). The register contains the name, data of birth, occupation, specialisation of the healthcare provider and authorization identification number.

⁵⁰ Det Centrale Personregister [Central Citizen Index]

⁵¹ See section 8 of Order nr. 1373 of 12 December 2006, Sundhedsstyrelsen [Board of Health] 2006, <u>https://www.retsinformation.dk/Forms/R0710.aspx?id=11055</u>.



3.3.3 The role of eCards

Denmark adopted official digital signatures instead of eCards Regarding eCards, the Danish government has decided to adopt an official digital signature as an alternative to electronic ID cards. Reasons for this decision are connected to pragmatic technical and economic choices, as the digital signature is said to be not the most flexible or secure form, but is expected to achieve widespread uptake more rapidly than other solutions and moreover is a cost-effective approach.

Thereby, the goal is to enable all Danes to conduct their business with public authorities securely from their home computers, using the same identification system for all eServices without having to pay additional charge for providing their identity or having to carry an eCard. In general, citizens can get free, software-based "official" digital signatures e.g. to access the portal Sundhed.dk and other secure websites containing personal information (taxation, housing etc.).

Sundhed.dk was launched in 2003 and acts as a single access point to healthcare services for both citizens and professionals. Citizens have access to both information and communication with the entire healthcare service through the web portal and it provides a framework for communication between citizens and professionals as well as between professionals.

In detail, citizens can log on to their personal web space and use the offered services, such as:

Services for citizens offered by Sundhed.dk:

- Book GP appointments
- Order medications and renew prescriptions
- Review medication and health data
- Communicate with healthcare authorities
- Register wishes in a Living Will
- Become an organ donor
- Access directory services, general and disease-specific health information
- Access national guidelines and basic information regarding hospitalisation

Sundhed.dk provides service for citizens and healthcare professionals in terms of access to data and communication infrastructure This portal will be further developed until 2012. Up to this point, the National Health Portal (Sundhed.dk) signed a cooperation agreement in 2009 with the portal for government services to citizens called "Borger.dk" for developing a health section and for coordinating strategy and IT development. The Health section on borger.dk will provide insight on health matters and will provide citizens with extra privileges and access to the digital portal for healthcare. Citizens will also have access to their personal health data from the "My sundhed.dk" through borger.dk's "My Page".

Denmark



As mentioned above, the official eHealth portal Sundhed.dk also provides services for health professionals. Through their digital signature professionals can log on to the portal. The portal provides a framework for communication between healthcare professionals about specific patients— as well as access to information about diseases/disorders and the healthcare service in general. Two examples of systems that can be accessed via Sundhed.dk are the Personal Electronic Medicine Profile (PEM), with medicine information from general practitioners, and e-journal, which contains excerpts of records from hospitals in Denmark.

By using special security certificates, healthcare professionals can also access laboratory test results and data stored in electronic patient records as well as utilise various resources (guidelines, clinical pathways, etc).

3.4 Legal and regulatory facilitators

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

Generally, the Danish legislation has been very flexible with regard to healthcare reforms whenever legal provisions were perceived as an impediment to technological progress. However, in the latest national eHealth Strategy more attention is paid to the regulation of data security and patient privacy. The necessity to investigate how technological solutions may be used to ensure compliance with the legislation was stressed.

The most important legal initiatives which prove necessary to pave the way for eHealth are: The separate rules contained in the Health Act regarding access for healthcare professionals to patient information stored in electronic medical records or registers; The rules contained in the Health Act regarding access to registries concerning medicine and vaccinations⁵²; The separate rules in the Consolidation Act on Legal Protection and Administration in Social Matters regarding automatic electronic exchange of information between the hospitals and home care services consolidated in August 2007, and the revised health act paragraph 37 on patient's right to see own data⁵³.

Act on Processing of Personal Data and the Act on Patient Data

⁵² Health Act, §157 act nr. 534, 26 May 2010

³ LovbekendgØrelse nr. 1047 af 27 august 2007 and Health Act § 57 act. Nr. 1521 27 December 2009.



Up to this point, legislation determines which types of healthcare professionals have access to which data and the conditions to be met before access can be given. Thereby, the Danish Data Protection Agency monitors all activities regarding the Act on Processing of Personal Data.

The Act on Processing of Personal Data entered into force in July 2000 and marked the end of a long legislative process in which there has been a discussion on whether the individual member states were free to build upon the EU Directive⁵⁴ or if it was a tool for harmonisation. In the end, it was decided that some of the central provisions of the Directive were harmonising, but that others are left to each Member State for own interpretation. This is reflected in the 2000 Act, which replaced the Public Authorities' Registers Act and the Private Registers Act. Rather than working in a vacuum, the new Act forms part of a complex legal environment, with a battery of other acts, ministerial orders and guidelines supplementing it. Since the Act on Processing of Personal Data entered into force in 2000, the Act has been amended several times - most recently on July 1st 2007. It is important to always read the Danish Act on Processing of Personal Data together with special, supplementing provisions in other Acts.

The Danish Health Act (2007) specifies the rules for transfer of data to healthcare professionals. It distinguishes between the disclosure of health information to other healthcare professionals in connection with treatment and care, collection of electronic medical data in connection with treatment and care and disclosure of health information for other purposes. There are special rules concerning disclosure of health information for scientific and statistical purposes and disclosure to third countries.

Finally, the Danish Board of Health issued legal guidelines regarding the liability and other legal matters in connection with practitioners' use of telemedicine. The guidelines refer to rules and principles in the existing legislation which also applies in connection with the use of telemedicine. The guidelines conclude that the use of telemedicine does not affect the usual legal liability and other legal obligations of practitioners⁵⁵.

3.4.1 Patient rights⁵⁶

In order to ensure patients' legal rights, a number of laws have been passed regulating patients' rights and the possibility of making complaints and receiving compensation for injuries caused by the Danish healthcare system. The main parts of patients' legal rights are gathered in the Health Care Act §§ 40-49. Thereby,

⁵⁴ Directive 95/46/EC

⁵⁵ Vejledning nr. 9719 of 9 november 2005.

⁵⁶ Datatilsynet; European Patients; Privireal 2005; Connected Digital Health in Denmark 2007; European Commission 2007; Rossing 2009


Denmark respects the patients' and citizens' rights as recommended by the Council of Europe and ratified EU directives such as 95/46, 97/66 and others.

In general, the patient has the right to opt out of gathering or communication of their health information for use in their treatment. The legislation requires proof of patient consent prior to delivery/transmission of data for other purposes e.g. research or administration. Patients consent is also needed whenever confidential information is shared with people and institutions outside of healthcare.

The Danish Health Act regulates the way patient related information must be handled in the Danish healthcare service. The ruling principle is that health information can be gathered electronically without patient consent. But the patient has to be informed and has the right to opt out.. There is an exception, though, which ensures that healthcare professionals involved in an actual episode of care will normally have access to pertinent information.

This means that information residing in department A may only be passed on to department B or to district healthcare when the information is to be used in an ongoing episode of care. In all other cases, the explicit approval of the patient must first be obtained. One of the most important objectives underlying this principle is to protect the patient from unintentional access to health information from the "outside world", like the place of work or social authorities. In practice, treatment of a patient mostly involves many different healthcare professionals from different sectors and together they provide a number of services such a prevention, examination, treatment and care. Here is a fine line between giving all information to relevant healthcare professionals within this network and protecting data against unauthorized access.

The provisions regarding professional secrecy and disclosure of information in the Danish Health Act originate from the Act on Patients' rights which came into force in 1998. At that time there was no widespread use of electronic medical records in the hospital sector, and the provisions regarding medical files in the Act on Patients' rights were designed to function in a non-electronic information environment. Later it became apparent that the wording of the provisions was not suitable in an electronic information environment where healthcare professionals are provided with direct access to electronic medical records and databases. As a result, the Health Act was amended in 2007. These provisions are explicitly dealing with the collection of electronic medical data.⁵⁷

Additionally, doctors are obliged to inform the patient about the illness, the possibility of treatment, the side effects etc. It is also possible to set up a "living will", informing doctors about one's wishes regarding pain, treatment and prolongation of life treatment if one is no longer able to communicate. Patients have a right to see their own medical records free of charge, and doctors or other medically trained staff have

⁵⁷ Sundhed; European Commission 2007; Castro 2009; Protti, Johansen et al. 2009



the obligation to interpret case records if the patient so wishes. Records after 1 January 2010 can be accessed electronically by the patient. (law nr. 534 27/12-2009).

Regarding mistreatment, a complaints system was established in 1988 for professional treatment in health service. The Patients' Complaints Board is an impartial public authority, which may express criticism of healthcare professionals not acting in accordance with commonly agreed professional standards or submit particularly serious cases to the public prosecutor with a view to bringing the cases before a court. Patients may seek compensation for injuries caused by examination or treatment in hospitals or by authorized healthcare professionals in private practice through the Patient Insurance Scheme, which was set up in 1992.

In relation to telemedical treatment, the Danish National Board of Health has issued legal guidelines regarding liability and other legal matters in connection with the use by physicians⁵⁸. The guidelines refer to rules and principles in the existing legislation which also apply in connection to telemedicine. The guidelines conclude that the use of telemedicine does not affect the usual legal liability and other legal obligations of physicians. There is no jurisprudence with regard to the liability of physicians using telemedicine⁵⁹.

3.5 Financing and reimbursement issues⁶⁰

The system of financing health and IT systems in Denmark is one of the most important advantages for the country in comparison to other EU member states. It has a significant impact on health IT adoption, because of the Danish single-payer healthcare system. This means that the costs and benefits of investing in eHealth are better aligned than in other countries, where multiple governmental and non-governmental entities pay for healthcare.

Furthermore, financial incentives for health IT adoption by healthcare providers are an effective policy tool to spur the use of health IT. In Denmark early efforts to computerize medical practices relied on financial incentives. In the 1980s for example, primary care physicians received small subsidies for submitting medical claims electronically by disk. Denmark has also set national reimbursement rates for email consultations and in 2008 had over 20.000 e-mail exchanges per month between patients and doctors.

⁵⁸ Telemedical Legislation: Vejledning nr. 9719 af 9. November 2005

⁵⁹ Dumortier 2009

⁶⁰ Connected Digital Health in Denmark 2007



Generally, the Danish government can afford to take long-term views and make investments that might not pay off fully in short term. This government involvement also leads to more accountability.

In sum, this implies that the Danish healthcare system is publicly funded: 85% of healthcare costs are financed through taxes and the majority is provided directly by the public sector. The healthcare system is based on a principle of free and equal access for all citizens. For financing of the majority of the regional and local healthcare expenditure, the state imposes a healthcare contribution tax – whereas 8% is from taxable income.

3.6 Evaluation results/plans/activities⁶¹

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

In Denmark it is one of the eHealth Strategy principles to optimise the prospects of successful digitalisation by ensuring scope for development, trials, testing and research. Thereby, a number of limited development and pilot projects – referred to as pathfinder projects – are planned to be launched in cooperation with authorities, professional organisations, research institutions, providers and other relevant parties.

Action, which is taken on behalf of these plans, includes:

- Pathfinder projects on a small scale at the local level
- Establishment of a framework to ensure ongoing external evaluation of new initiatives

- Ongoing revision of action plans in order to provide a basis for using the plans actively to gain an overview of and manage the overall developments and coherence between individual projects

A specific study, which has been carried out by Deloitte in April 2007, conducted a review of the work carried out so far in relation to electronic patient records. The EHRs had been commissioned by the Board of Organisation of the Connected Digital Health Organisation (SDSD) – at that time known as EPR organisation. The review was performed with assistance from an independent panel of experts. The review also served as input to the new strategy for the years 2008-2012. Earlier

⁶¹ Voss 2005; Stroetmann, Jones et al. 2006; Wanscher, Pederson et al. 2006; Connected Digital Health in Denmark 2007; Deloitte 2007



evaluation studies of electronic patient records (EPR) include EHR Observatory status reports from 2000-2006⁶² and Evaluation reports of B-EPR implementations ⁶³⁶⁴.

At the European level, an evaluation of specific cases/eHealth applications has been carried out as part of the eHealth Impact Study. Among the "100 studies - an overview of good practice in Europe"⁶⁵, some are from Denmark. In these studies economic impact of eHealth is underlined. Evaluation of Danish eHealth applications include: Baltic eHealth - Improving Life in Rural Areas of the Baltic Sea Region by eHealth Services; Healthcare delivery optimisation through telemedicine; Danish Health Data Network and the Danish eHealth portal.

4 Outlook

The Danish eHealth system has two characteristics, which make the country a frontrunner in the field compared to other EU member states: First, IT applications in the field of health are already deeply rooted at a local or regional level. This means that mature systems are in place not only for communication between health professionals, but also for patient access and data management, which leads to a certain amount of trust into health technology. Second, Denmark has a long history of financing and developing new IT applications in governance and health. Examples for this can be found in the deployment of patient summaries and in the area of policy documents, as 1996 the "Action Plan for EHRs" was created.

But the mature local IT systems also pose a challenge for future eHealth developments in Denmark, as the creation of national platforms and the combination of different systems is a difficult task. Especially for the development of the central prescription server and the medicine profile, the interoperability and coherence of these systems has to be assured.

In sum, Denmark stands out because of it's a) early adoption of ICT and electronic message communication among GP's partly due to the financing mechanisms, partly due to the pragmatic approach and ongoing work by MedCom, b) national registries some of which were established many years ago c) the establishment of shared services e.g. the medicine profile and the e-journal, and joint solutions/projects, such as the national eHealth portal (sundhed.dk) its single-payer financing system and the far-reaching development of patient data and access platforms. These unique features make the Danish eHealth system a frontrunner in Europe and give good examples for other European member states.

⁶² epj-observatoriet [EHR-Observatory] 2006

⁶³ Appel 2005

⁶⁴ Bosse 2007

⁶⁵ empirica



5 List of abbreviations

CSC	Computer Science Corporation
DNRP	Danish National Patient Registry
DRG	Diagnosis Related Group
EC	European Commission
EEA	European Economic Area
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPR	Electronic Patient Record
epSOS	European patients Smart Open Services
ERA	European Research Area
EU	European Union
GDP	Gross Domestic Product
GP	General Practitioner
НСР	Healthcare Provider
HL7	Health Level Seven International (authority on standards for interoperability)
HMO	Health Maintenance Organisation
HPC	Health Professional Card
ICT	Information and Communication Technology
ID	Identification (e.g. number, card or code)
IHTSDO	International Health Terminology Standards Development Organisation
IT	Information Technology
LSP	Large Scale Pilot
NPI	National Patient Index
OECD	Organisation for Economic Co-operation and Development
PHS	Personal Health System



R&D	Research and Development		
SDSD	Connected Digital Health Organisation		
SNOMED	Systematized Nomenclature of Medicine-Clinical Terms		
WHO	World Health Organization		



6 Annex

6.1.1 Annex 1: Compound indicators of eHealth use by GPs

Compound indicator name	Component indicators	Computation
Overall eHealth use	 Electronic storage of individual medical patient data Electronic storage of individual administrative patient data Use of a computer during consultation with the patient Use of a Decision Support System (DSS) Transfer of lab results from the laboratory Transfer of administrative patient data to reimbursers or other care providers Transfer of medical patient data to other care providers or professionals ePrescribing (transfer of prescription to pharmacy) 	Average of component indicators
Electronic storage of individual medical patient data	 A2a - Symptoms or the reasons for encounter A2c - Medical history A2c - Basic medical parameters such as allergies A2d - Vital signs measurement A2e - Diagnoses A2f - Medications A2g - Laboratory results A2h - Ordered examinations and results A2i - Radiological images A2j - Treatment outcomes 	Average of component indicators
Electronic storage of individual administrative patient data	 A1 - electronic storage of individual administrative patient 	A1 value
Use of a computer during consultation with the patien	- B2 - Computer use during consultation t	B2 value
Use of a Decision Support System (DSS)	 B3a - Availability of DSS for diagnosis B3b - Availability of DSS for prescribing 	Average of component indicators
Transfer of lab results from the laboratory	- D1e - Using electronic networks to transfer prescriptions electronically to dispensing pharmacists?	D1e value
Transfer of administrative patient data to reimbursers or other care providers	 D1a - Using electronic networks to exchange of administrative data with other healthcare providers D1b - Using electronic networks to exchange of administrative data with reimbursing organisations 	Average of component indicators
Transfer of medical patient data to other care providers or professionals	 D1c - Using electronic networks to exchange medical data with other health care providers and professionals 	D1c value
ePrescribing (transfer of prescription to pharmacy)	- D1d - Using electronic networks to transfer prescriptions electronically to dispensing pharmacist	D1d value

Dobrev, Haesner et al. 2008



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eHealth in Denmark

eHealth as a part of a coherent Danish health care system



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A Vision for eHealth in Denmark

The vision for the health care system in Denmark is to provide coherent clinical pathways through the various parts of the health care system, focusing on the needs of patients and high quality of treatment.

One of the main prerequisites for establishing a coherent and cooperating health care system is to ensure that all health care professionals dealing with a patient have easy access to relevant patient information where and when it is needed. This strengthens the base for decision making and enhances patient safety.

Digitalisation is the key element in achieving this goal by giving health care professionals access to data and examination results across the entire health sector. eHealth is also vital for leveraging secure, efficient work processes, high productivity and high standards of health care delivery.

There is an extensive need for digital solutions in the health care system. In the coming years, growing numbers of senior citizens and the introduction of new treatments will increase the pressure on health sector resources. In addition, both patients and the health care system can benefit from empowering patients to manage their own health by providing better access to their own health data and by the use of telemedicine and home-monitoring technologies.

As this brochure aims to illustrate, Denmark has come a long way already. Several international studies rank Denmark among the leading countries when it comes to uptake of ICT solutions in the health care sector.

The ambition in the coming years is to integrate and streamline the way patient data are accessed and shared across the health care system, in order to make all relevant data accessible when needed and to accelerate the implementation of thoroughly tested solutions across the entire health service.

The brochure contains an introduction to existing and future Danish eHealth solutions that connect the Danish health care system and the context in which they have been established. In addition, the brochure touches upon the prerequisites for working with eHealth in Denmark, including the governance setup and descriptions of the main stakeholders.

We hope you will find the information interesting.

Astrid Krag

Danish Minister of Health Bent Hansen

President of Danish Regions Erik Nielsen

Chairman of Local Government Denmark



Denmark is among the frontrunners

"The SIMPHS research has identified Denmark, together with England and Scotland, as leaders in terms of mainstreaming telehealth in Europe under the combination of demand side factors, high eHealth deployment, good governance models and in terms of engagement of key stakeholders in tiers of care and the value chain."

> Strategic Monitor on Personal Health Systems (SIMPHS) European Commission, JRC IPTS, March 2012

"Denmark Leads the Way in Digital Care"

> New York Times, January 11, 2010

"In Denmark's Electronic Health Records Program, a Lesson for the U.S."

> Time Magazine, April 16, 2009

Why eHealth?

Well functioning eHealth solutions hold the potential to benefit citizens, patients and health care professionals in several ways:

- Improved flexibility and effective ways of organising treatment, leading to improved quality and safety in treatment and care.
- Enabling more individualised treatment by empowering patients and involving them in their own treatment.
- Better working conditions for employees in the health and welfare sectors by improving workflows and reducing time spent on gathering information about a patient from other parts of the health care sector. This allows doctors and nurses to devote more time to patients.

Furthermore, eHealth contributes to better use of the resources allocated to health care by making analyses and assessments easier to execute on the basis of the various data on activity and expenditures that eHealth solutions are gathering.

Today, eHealth is very commonly used throughout the whole Danish health service and supports many work processes, including processes that reach across organisations and sectors.

But as new technologies emerge, the field still holds great potential to contribute to the development of a more modern and efficient way of delivering health care.

For this reason, it is the ambition to implement and integrate thoroughly tested solutions more speedily in the coming years, with better coordination across the entire health service to further harvest the benefits from eHealth across the whole of the health care system.



"Our analysis of available literature and data indicates that three countries – Denmark, Finland, and Sweden – are definitively ahead of the United States and most other countries in moving forward with their health IT systems. These three Nordic countries have nearly universal usage of electronic health records (EHRs) among primary care providers, high rates of adoption of EHRs in hospitals, widespread use of health IT applications, including the ability to order tests and prescribe medicine electronically, advanced telehealth programs, and portals that provide online access to health information."

> Information Technology and Innovation Foundation 2009, "Explaining International IT Application Leadership"

"From the data collected for this study, Denmark, the Netherlands, Finland, Sweden and the UK emerge as the European frontrunners in eHealth use by General Practitioners."

> Benchmarking ICT Use among General Practitioners in Europe, European Commission April 2008

The Danish health care system at a glance

The layout of the Danish health care system and the Danish political system forms an important basis for the work on eHealth in Denmark.

Health care in Denmark is based on two main principles:

- Free and equal access to public health care. This includes general and specialised practitioner services and all public hospital services. Private co-payment includes dentists and out-of-hospital medicines and aides.
- **Universal coverage.** All residents in Denmark are entitled to public health care benefits in kind.

The public health care system is organised in two main sectors: primary health care and the hospital sector.

The **primary health care sector** deals with general health problems and care and consists primarily of general practitioners, practising specialists, practising dentists, physiotherapists and home nursing.

Primary health care also includes preventive health schemes, public health care and child dental care.

The general practitioners occupy a central position in the Danish health care system as the patients' primary point of entry to health services. The general practitioner ensures that the patient is given the right treatment and is referred to the right professionals in the health service. The general practitioner is thus the coordinator and the person with professional responsibility for referring patients to hospitals, specialists and other professionals.

	Denmark	OECD average
Number of doctors (pr. 1,000 inhabitants)	3.4	3.1
Number of beds at public hospitals (pr. 1,000 inhabitants)	3.5	4.9
Life expectancy	79.0	79.5

Source: OECD (2009)

The **hospital sector** deals with medical conditions that require specialised treatment, equipment and intensive care.

As a rule, a general practitioner must refer the patient to a hospital for medical examination and treatment unless it is a question of an accident or acute illness. It will normally also be necessary to be referred by a general practitioner for treatment by a specialist.

Since 1993 patients have had the right to choose between all public somatic public hospitals for treatment. Since 2002, so-called extended free choice has given patients the right to choose publicly financed treatment at a private hospital if waiting times at public hospitals are too long.

Public health expenditures

	Denmark	OECD average
Total expenditure (USD pr. capita)	4,348	3,233
GDP percentage	11.5	9.6

Public expenditure constitutes approx. 84 per cent of total health expenditure. Private health care expenditure mainly covers out of pocket expenditures for pharmaceuticals and dentistry.

The state imposes a health care contribution tax for financing the majority of regional and local health care expenditure. This tax is 7 per cent on taxable income.

Source: OECD (2009)



Political and administrative levels in the health care sector

Like Denmark as a whole, the health care sector has three political and administrative levels: the state, the five regions and 98 municipalities.

The health care service is organised in such a way that responsibility for the services provided is placed at the lowest possible administrative level. Services can thus be provided as close to the users as possible.

National level

The task of the state in health care provision is to initiate, coordinate and advise on national health policy at a general level.

The Ministry of Health, in its capacity of principal health authority, is responsible for drawing up overall national health policies and legislation on health care.

The Ministry also draws up guidelines for general planning within the health sector and operation of the health care service.

Regional level

The five regions in Denmark are run by elected boards and are the main service providers in the Danish health care system. Their responsibilities include:

- All hospital and psychiatric treatment
- Parts of the primary health care system:
 - General practitioners (family doctors)
 - Private practising specialists
 - Dental services for adults
 - Physiotherapy

The regions do not collect taxes. Instead, the regional health care services are financed through a block grant from the state, a state activity-related subsidy and a municipal contribution.



98 municipalities



Local level

The 98 municipalities are the local administrative bodies with an average of approx. 57,000 inhabitants. The municipalities are responsible for a number of tasks including social services, primary schools and care for the elderly. In the field of health, the municipalities are responsible for:

- Home nursing and homes for elderly people with care facilities and associated care staff
- Public and school health care
- Child dental treatment
- General disease prevention
- Rehabilitation

The municipalities finance approx. 20 per cent of the total expenditure on health care in the regions. The payment consists of an activity-related contribution depending on the citizen's use of hospitals. The purpose of the local contributions is to encourage the municipalities to initiate efficient preventive measures for their citizens with regard to health issues.



Major investments in new hospitals

In the coming years, the regions are to implement significant changes in the hospital structure in Denmark. Between 2010 and 2020, more than 5 billion euros will be invested in large new hospitals and expansion of already existing hospitals. This will result in a renewal of approx. 1/3 of all hospital square meters in Denmark.

A total of 16 new hospitals are being designed and planned. These hospital investments will lead to a modern, up-todate hospital structure, where acute and highly specialised treatment will be centralised at fewer locations.

The plans also include large-scale investment in ICT and appliances. For this reason, a substantial amount has been dedicated to investments in equipment and technology, which will be realised during the next 10 years.

Current Danish eHealth solutions

As the previous chapter describres, health care services in Denmark are shared among various sectors and organisations.

In order to ensure coherent health care delivery, a number of current eHealth solutions contribute to connecting the Danish health care system digitally.

MedCom messages - digital exchange of health data

MedCom was established in 1994 with the purpose of developing nationwide communication standards for the most common messages between public hospitals and general practitioners as well as private companies linked to the health care sector, e.g. pharmacies.

The messages cover the most frequent text-based clinical messages in the Danish health care, e.g. discharge letters, referrals, lab test orders, e-prescriptions and reimbursement from public health insurance.

From a rather slow start with less than 4,000 documents in the first year, the exchange of health care documents is now almost fully electronic with more than 60 million messages sent in 2011. In reality practically all frequent documents in the health care sector are transferred electronically between health care professionals.

Type of message	% digital
Discharge letters from hospitals to GPs	99
Referrals from GPs to hospitals	81
Lab results from laboratories to GPs	99
Lab test orders from GPs to laboratories	99
e-Prescriptions from GPs to pharmacies	85
Reimbursement from GPs to public health insurance	99
Notifications of admission / Notifications of discharge	
from hospitals to municipalities	98
Rehabilitation plans from hospitals to municipalities	80

Source: MedCom

The focus is now on digitalising a number of messages sent between hospitals and home nursing in municipalities, including discharge letters and home nursing plans. These messages are expected to be fully digitalised by the end of 2012.



Sundhed.dk - the official web portal of the public health services

Sundhed.dk ("health".dk) is the official Danish health website providing access to information for citizens, patients and health care professionals.

Sundhed.dk for the patient

- In a secure part of the website, the patient has access to personal health data on treatments and notes from hospital records, information about medicine and about visits to the GP etc.
- Access to various e-services including making appointments with GPs, prescription renewals and electronic communication with the GP.
- Access to information on waiting times at all public hospitals and ratings of hospitals in terms of patient-experienced quality and service.
- Patient networks give the patient the possibility to discuss their own disease, treatment etc. with other patients with a similar diagnosis, especially relevant for patients with a chronic disease.
- Access to sundhed.dk's handbook for patients, which consists of 3.000 articles with information on diseases and treatment



Sundhed.dk for the health care

- The main entry for access to existing patient data that is not already accessible in the health care professional's own EHR system. This typically includes access to data in **e-Journalen** and **the Shared Medication Record**. Every access is logged with information on time of access and the name of the health care professional's organisation.
- Access to the professional version of sundhed.dk's handbook for physicians, covering a wide range of health care with articles, guidelines, educational programmes, tests, video animations etc.

In the coming years, sundhed.dk aims to support the overall trend in health care delivery in terms of changes in the relationship between health care professionals and patients with respect to supporting the patient's management of a healthy lifestyle, disease prevention and a stronger connection between treatment and the patient's own efforts. One example would be to give the patient the possibility to register various health data directly in the web portal.



Hanne, 38 years of age

Hanne has an appointment with her GP to receive the results of a routine smear examination. The results indicate a risk of cancer, and she is electronically referred for examination at the hospital.

Hanne is anxious about whether the hospital she has been referred to is good enough, so she checks figures on patient satisfaction and quality in care on sundhed.dk. She also realises that she hasn't remembered all the information that the GP gave her, so she looks up the handbook for patients on sundhed.dk, which contains 3,000 articles with information on diseases and treatment.

Hanne has the surgery, and through cell analysis that is confirmed when she visits her GP she is informed that the cells were cancer cells. Afterwards, she starts chemotherapy treatment at the hospital.

At a later visit to the GP, the doctor consults e-Journalen and the Shared Medication Record in the part of sundhed.dk dedicated to health care professionals in order to read Hanne's medical record in the hospital EHR system and to see what kind of medicine the hospital has prescribed for her.

During the treatment, she discusses her situation with her sister. She doubts whether she has understood everything that has been said at the hospital. By using e-Journalen on sundhed.dk, she also gets access to her own medical record from the hospital. Furthermore, she consults the patient information in sundhed. dk's handbook for physicians to understand all the medical terms.

She also feels the need to talk other patients in the same situation. She is told about patient networks on sundhed.dk and creates a profile so she can read and reply to posts from other patients in a similar situation and from health care professionals.

Everything indicates that Hanne will make a full recovery.

Based on a fictional story

Accessible data in the e-Journalen system across Danish hospitals



"e-Journalen" - digital access to electronic medical records at hospitals

The **e-Journalen** ("e-record") system gives patients and health care professionals digital access to information on diagnoses, treatments and notes from EHR systems in all public hospitals. 30–40 per cent of the hospitals also provide access to information on medicine and sample results from laboratories.

By the end of 2011, the system contained health data on more than 85 per cent of the Danish population.

Clinicians at hospitals have access to **e-Journalen** directly through the hospital's EHR system, while GPs can access the system through **sundhed.dk**. Furthermore, patients can also gain access to their own data via **sundhed.dk**.

Use of the system has increased steadily since its introduction in 2007. In 2011, the system had more than 1.2 million entries, primarily by hospital physicians and patients.

Use of the e-Journalen system 2007-2011



The e-Journalen has benefited Danish health care in several ways:

- Increased patient safety and improved patient treatment by providing a more solid ground for decision making as doctors have better access to existing patient data.
- Connection of various EHR systems used at the Danish public hospitals in a cost-effective and pragmatic way.
- Supported the exchange of patient data between hospital departments more cost-effectively. Prior to the **e-Journalen** system, information was often delivered by ordinary mail or fax.

Furthermore, the e-Journalen has contributed to openness in the health sector by providing the patient with easy access to own health data. This has created a stronger base for involving and activating the patient in relation to his or her treatment as well as increased patient empowerment.



Erna, 70 years of age

Erna has had diabetes for many years. Due to the illness, she has been having some trouble with ulcers on her legs and feet.

For this reason, she has to go for regular checkups at the hospital 50 kilometres away from her home. She has to use half a day on each visit – sometimes even more if the doctor is late.

The last time she went to the hospital, the doctor told her that it is possible to avoid some of the hospital visits if a home nurse from her own municipality takes pictures of Erna's ulcers and forwards them to the hospital. Erna finds the idea interesting and agrees to try it out.

A few days later, the home nurse, who has been specially trained, visits Erna for the first time. The nurse uses her mobile phone to take a picture of Erna's ulcers and the picture is digitally transferred to a database.

At the hospital, the doctor examines the photos of Erna's ulcers. He makes sure that the repair is progressing as expected and lets the nurse know that Erna doesn't have to go to the hospital for the next visit.

Half a year later, the ulcer has returned. By checking the pictures sent by the home nurse, the doctor concludes that a change in the treatment is necessary. He calls Erna to the hospital. The doctor prescribes a different kind of ointment.

A few weeks later, Erna's ulcer has almost disappeared.



Projects currently being implemented

At present, two significant projects are being implemented in order to further digitally connect the Danish health system.

The Shared Medication Record - a digital overview of a patient's current medication

Lack of full knowledge about a patient's medication often leads to medication errors and hospital admissions.

The incomplete knowledge is often due to the fact that the main source of information on the patient's medication typically is the patient him or herself. As a patient, it can be difficult to remember all currently prescribed medication as well as the correct name of the medicine. As a consequence, the clinician often receives incorrect or incomplete information. This can potentially be harmful to the patient.

To counter this problem, **The Shared Medi**cation Record ("Fælles Medicinkort") is being implemented across the Danish health system. The system consists of a central database containing information on all Danish citizens' medicine dispensed during the previous two years as well as an updated list of every patient's current medication.



Once the implementation is completed, citizens, doctors, emergency physicians and other health care professionals will have digital access to updated information on the patient's prescribed medication.

Access is established through local EHR systems at hospitals and in private practices or via **sundhed.dk**. The patient can also access the shared medication record through **sundhed.dk**.

The Shared Medication Record will contribute to a number of benefits including:

- All health care professionals involved in the treatment of a patient will have digital access to up-to-date information on the patient's current medication.
- Increased likelihood of correct medication across the various parts of the health care sector.
- A reduction in the need for the patient to remember details about their own medication.
- Easier handling of medication information between health care professionals. Previously, information about a patient's medication from the patient's GP was often collected from hospitals by phone or fax.

The project will be fully implemented at all Danish hospitals before the end of 2012.



Telemedicine in Denmark

The use of telemedicine is becoming more widespread in the Danish regions and municipalities. After a rather large number of minor 'stand alone' projects, mainly by local entrepreneurs, the health care system is now moving into a phase where large-scale projects involving telemedicine are being initiated.

Two examples are COPD and diabetic ulcer projects, often conducted in close cooperation between municipal home nursing and hospitals. The projects show promising results and are an indication of the breakthrough in the use of telemedicine that is expected to take place in the coming years.

Most telemedicine projects in Denmark are centred around three main themes:

Long-distance monitoring: These projects cover a wide range of initiatives where the patient's health status is monitored at a distance, often from the patient's home. The projects include self-reported monitoring of chronic diseases and assisted telemedicine, where the patient, assisted by a nurse, conducts tests under video supervision by the specialist at the hospital. The purpose is to prevent visits to the hospital. This benefits patients and reduces costs.

Projects involving video conferencing: The aim of these projects is to support communication either between health professionals (from GP or municipal nurse to hospital or between hospitals), or between patients and health professionals. Video conferencing has been used in the municipalities to strengthen the dialogue between municipalities and medical wards at hospitals and in staff training and supervision. Secondly, municipalities and hospitals can use video conferencing to obtain second opinions from specialists.

Digital exchange of photos: The most widespread use of this technology has been the exchange of photos of diabetic ulcers for examination purposes between home nurses in municipalities and specialists at hospitals. In some parts of the country, using telemedicine for ulcer examination is already part of the daily routine, whereas others are piloting the technology. It is broadly accepted that the solution can be beneficial with respect to both quality and costs.

The National Patient Index and the National Health Record

Today, patient data are stored digitally in various databases across the health care sector. However, health care professionals and patients often lack digital access to this information.

The ambition in the two connected projects "The National Patient Index" and the "National Health Record" is to give health care professionals and patients easy access to data on the patient when needed by creating a digital overview of existing health data.

The National Patient Index is an infrastructure project that makes it possible to search for existing data on a patient in the data sources that are integrated into the index. Furthermore, it contains a number of security measures to ensure secure use of the system.

Initially, The National Patient Index will provide access to the following data sources:

- Medication data from The Shared Medication Record.
- Information from EHR systems at hospitals and from EHR systems at GPs.
- Data from laboratories.
- Data on vaccinations from the Danish Vaccination Register.
- Material from an interregional radiology information system/ picture archiving communication system.
- Data from the national patient register containing data on all hospital admissions, both ambulatory and hospitalisation.

Additional data sources are expected to be added in the coming years.

At the same time, **The Regional eHealth Organisation** (RSI – see below) is establishing a **National Health Record**, which is an expansion of the current **e-Journalen** system (see above). The National Health Record will display data from the data sources in The National Patient Index in a coherent and intelligent user interface.

The system is planned to be fully implemented in the clinical work stations at all public hospitals by the end of 2013. The patient will have access via sundhed.dk.




By establishing **The National Patient Index** and **The National Health Record**, clinicians and patients will have access to a more complete overview of existing patient data. This will benefit health care professionals and patients in several ways by providing:

- A clinical tool that enables digital sharing of data across borders and sectors in the health care system.
- A tool for gaining digital access to patient data not already stored in local EHR systems.
- Support in decision-making in relation to referral, elucidation and treatment of a patient.
- Giving citizens access to a broader range of own health data thereby establishing a foundation for improved dialogue, better insight in their own health condition and improved possibility for active involvement in their own treatment.

Denmark – a leader with telehealth deployment in Europe

The Strategic Intelligence Monitor on Personal Health Systems research on "Integrated Personal Health and Care Services" (IPHS) in Europe has identified Denmark as one of the leading European countries that have succeeded in taking telehealth initiatives beyond the pilot stage, into de facto mainstreaming in care pathways.

The analysis of five Danish best cases has helped IPTS identify key elements for successful mainstreaming which other EU countries could learn from.

Governance & funding mechanisms

Pilots and projects in Europe tend to stumble in terms of securing long-term funding and sustainability. The availability of funding has been key to enable mainstreaming in Denmark. In addition, an integrated governance model, engaging all stakeholders, combined with the adaptation of the legal framework, have also contributed to the decisions on mainstreaming.

Care re-organisation

Successful telehealth implementation requires re-organisation of care. The already existing very good relationships between primary, hospital and social care have greatly contributed to such a re-organisation in Denmark, thereby making way for enhanced telehealth deployment.

Incentives

Incentives in all tiers of care need to be aligned if telehealth is to succeed. Denmark is one of the pioneers having introduced specific Diagnosis Related Groups (DRG) for some telehealth services.

• eHealth deployment

High levels of eHealth deployment become a major asset and enabler of integrated complex solutions like telehealth and care delivery, while at the same time stimulating innovation in the implementation of interoperable solutions. Denmark through the pioneering work of MedCom since the 1990s has managed to create the digital infrastructure that underpins scalable eHealth deployment.

The SIMPHS findings on the Danish case and comparisons with other countries and regions of Europe enable the wider eHealth community to draw important lessons.

While many European countries are still struggling to overcome barriers, the Danish experience shows that these barriers if managed properly can be turned into drivers. This gives hope that European healthcare systems, with the support of ICTs, can adapt to meet the challenges of our ageing societies.

Strategic Monitor on Personal Health Systems (SIMPHS) European Commission, JRC IPTS, March 2012

Governance model and main stakeholders

A core feature in the field of eHealth is to ensure widespread implementation of eHealth solutions in order to fully reap the benefits.

For this reason, the final chapter is dedicated to a description of the main stakeholders in the field of eHealth in Denmark and the governance setup in which they operate.

Division of labour and responsibilities

For many years the development of eHealth in Denmark has been based on cooperation between all involved parties: the government, the regions, the municipalities etc.

This has brought the development to a level where nearly all basic information between the various sectors has been digitalised and where a large number of eHealth solutions, including various EHR systems, have been introduced in almost all parts of the health system.

In recent years, efforts have been concentrated on integrating and streamlining the way patient data are accessed and shared across the health system to make all relevant patient data accessible when needed.

In order to achieve more coordinated and speedy development, in June 2010 the Danish Regions and the Danish Government agreed on a number of changes in the organisational setup in the field of eHealth.

The main focus of the agreement is to ensure a clearer division of labour between all parties involved including the Ministry of Health and the five regions. The agreement states that the Ministry is responsible for overall development and national coordination and prioritisation. Within this framework, the regions are responsible for investments in and the implementation of specific eHealth solutions.

As a part of the agreement, a board has been established to advise the health minister. The advisory board consists of representatives from the government, the regions and the municipalities. The role of the board is to coordinate and follow the overall strategy and development within eHealth, to initiate new national eHealth projects etc.

Furthermore, the agreement contains a number of milestones for the development within eHealth till the end of 2013. The milestones include:



- An ambitious plan for the integration and consolidation of the EHR systems that have been in introduced at public hospitals over the years. In 2007 there were 27 different EHR systems in use across all public hospitals. This will be reduced to five coherent EHR landscapes (one in each of the five Danish regions) before the end of 2013.
- The establishment of **The National Patient Index**, which will give all health care professionals access to an overview of all relevant existing data on a patient irrespective of where in the health care system the data are stored. This system is planned to be integrated in EHR systems at hospitals before the end of 2013.

The agreement, moreover, states that investments in eHealth systems must be financed by the party that benefits from the investment.

Prerequisites for eHealth in Denmark

A number of favourable prerequisites generate a solid basis for working with eHealth solutions in the Danish health care system.

Ranking of Denmark in ICT indicators

	2006	2007	2008	2009	2010
World Economic Forum: Networked Readiness Index	1	1	1	1	3
The Economist Intelligence Unit: Digital Economy Rankings	1	1	5	1	2
OECD: Broadband Growth and Policies	1	1	1	2	N/A
IDC: Information Society Index	1	1	1	1	1

Source: Agency for the Digitalisation

An ICT-ready society

The use of ICT is an integrated part of Danish society. Denmark is among the leading nations in the world according to a number of international indicators on the use of ICT, digitalisation of the public sector etc.

Additionally, the Danish population are among the most ICT ready in Europe. According to a recent Eurostat study, 78 per cent use the Internet on a daily or almost daily basis and 90 per cent of Danish households have internet access.

A unique personal identifier

A digital identification system is a central prerequisite for ensuring verification of patients in various ICT solutions across the health care sector.

The Danish personal identifier, also known as the civil registration number, is a unique personal identification number that each Danish citizen is provided with at birth. The system was introduced in 1968. Every citizen in Denmark can be identified by the use of this system and it is used for identification in all areas, i.e. taxation, social services, banking, health care etc.

To enable online verification (eID) on various websites, a Danish digital signature was introduced in 2003. The signature is linked to the personal identification number.

In 2010, the system was expanded to the "NemID" ("Easy"-ID) system, which is a common secure login solution that can be used on all public websites in Denmark and for Internet banking.

A Danish citizen can use the NemID from any computer, both in Denmark and abroad. For this reason, the system consists of a two-factor authentication solution based on a pin code and a key card with single use codes.



A long tradition of health registries and databases

Denmark has a long tradition of thorough monitoring and registration of patients who have been in contact with the health sector. Some databases have been maintained for more than 30 years.

The Ministry of Health is responsible for maintaining a number of databases on health statistics including the general health of the population as well as morbidity and mortality. Information concerning the organisation and finances of the health care sector is also registered.

Additionally, Danish databases on clinical quality contain information on the performance of the health care system. The databases are all defined to a certain area of disease or a medical procedure e.g. breast cancer, heart failure and chronic obstructive lung disease. A network of more than 50 national databases has been established containing information on more than 60 different areas of disease.

The Danish personal identifier makes it possible to trace patients across the various databases, which creates unique possibilities for research and development.

The Danish Health Data Network for secure data exchange

The Danish Health Data Network (DHDN) gives the entire health sector in Denmark the possibility of offering their services to all the connected organisations through one secure digital connection.

The philosophy behind DHDN is that the parties in the health sector will have all their communication needs met via the same network connection. This makes the network the electronic exchange point for all communication across the health care system, regardless of whether the users belong to the public or private sector.

Other than providing backbone network services for the Danish health care sector, DHDN is also used in various international projects with connections to Norway, Sweden, Estonia, Lithuania, Germany and Spain.

DHDN also delivers video conferencing services to all connected organisations in order to minimize the problems in communicating between different video conferencing platforms.

Danish legislation concerning eHealth

Danish legislation governing eHealth is relatively accommodating compared to other countries. Doctors, dentists, midwives, nurses, home nurse assistants, radiographers and paramedics all have the possibility to digitally obtain health data on a patient – irrespective of whether the data are historical or current.

However, it is a requirement that the information is necessary for the current treatment of a patient, and only information relevant for the treatment can be obtained.

All public hospitals must keep a log file of the health care professionals who have accessed a patient's data. As part of security measures, random samples can be taken of the employee's access to files in the EHR systems in order to avoid misuse of the system.

Furthermore, a patient can deny health care professionals access to information on the patient's health data at any time. In other words, the patients have control over their own health data.



Interpretation via video conferencing in all Danish Hospitals

Approx. 150,000 interpretations are carried out in Danish hospitals and at GPs every year. The process concerning the interpretation is frequently time-consuming and inflexible. The health care professional has to make sure that the interpreter and the patient are present and ready at the same time, and the health care professional can be late due to delays at the hospital. For this reason, the interpreter sometimes has to leave early if another appointment has been scheduled.

Since 2010, a project concerning the use of interpreters via video conferencing has been undergoing implementation in all public Danish hospitals. Interpretation through video conferencing equipment contributes to more efficient use of the interpreter, as the video link will be established only when the health care professional and the patient are ready. Additionally, the interpreter does not have to spend time travelling to and from the hospital.

It also contributes to more flexible access to interpretation services, especially in situations where acute treatment is necessary, thereby potentially leading to higher quality in treatment and greater patient satisfaction.



Ministry of Health

According to Danish health legislation, the Minister of Health has the right to formulate specific requirements about the use of ICT in the Danish health care system, including requirements concerning standardisation, use of common infrastructure etc.

The Ministry of Health is responsible for effectuating the intentions of the law. This implies ensuring enhanced overall national coordination of the development of eHealth throughout the Danish health care sector.

This task is being carried out in close collaboration with all relevant parties in order to manage the processes leading to the establishment of uniform rules and frameworks for eHealth in Denmark.



STATENS SERUM INSTITUT NATIONAL INSTITUTE FOR HEALTH DATA AND DISEASE CONTROL



To handle the responsibilities, the Danish National Board of eHealth was established in 2011 as an agency under the ministry. The agency is responsible for:

- Developing and maintaining a national catalogue of ICT standards to be used in the Danish health care system. The catalogue contains more than 400 standards primarily based on standardisations that have been laid down internationally.
- Consolidating national health registries and systems to ensure more efficient operation and development.
- Improving national services provided to the various parts of the health care system, including access to real-time data for financial and quality control, standardising external interfaces for reporting health data etc.
- Implementing specific intersectoral initiatives within eHealth such as the Shared Medication Record and the National Patient Index as agreed in annual budget agreements and based on politically determined targets and milestones.



Danish Regions

The five regions have formed an interest organisation, Danish Regions, which coordinates the common interests of the regions at national level.

This concerns i.a. negotiating the annual financial framework for the regions with the government as well as agreements with the private practising sector including GPs and dentists.

The regions are working on improving the quality of the Danish health care system. The fundamental idea is that improved quality of treatment benefits both the patients and the economy because patients avoid longer stays in hospital as well as readmissions. ICT is viewed as a key enabler in this work.

eHealth is an integrated part of all hospitals' business and work processes, thus supporting the overall goals of the hospital sector. The benefits achieved by implementing eHealth should be seen as an integral part of the organisation as such and cannot be separated from the core business.

The Regional eHealth Organisation (Regionernes Sundheds-IT organisation – RSI) was established in 2010 to accelerate and coordinate the implementation of eHealth across the five regions.

RSI is managed by board members from all five regions and Danish Regions. All projects are carried out with one of the regions as the main principal.

RSI has formulated 24 ambitious goals for eHealth development, all of which have specific deadlines. Examples of the goals are:

- Single sign-on to all major ICT systems at all hospitals before the end of 2013.
- Electronic overview boards on all major emergency wards before the end of 2011.
- Digital exchange of X-rays between all hospitals before the end of 2012.
- Citizens' access to own data in the **e-Journalen** system before the end of 2010 as a part of a combined patient empowerment strategy.

The cooperation within RSI has already come a long way. Currently (February 2012), 13 of the 24 goals have been reached and new goals are being formulated.



In 2011, the government, Local Government Denmark and Danish Regions agreed on a new strategy for the continued work of digitalising the public sector in Denmark. The strategy includes a number of ambitious goals for digital communication between citizens and the public sector.

Today, citizens can already handle most of their communication needs with the public sector online. Most Danish citizens check their tax returns on the Danish Tax and Customs Administration's website. Students sort out their grants online. New parents can check the rules for maternity and paternity leave on Borger.dk ("Citizen".dk – The National Citizen Portal).

To further increase the use of e-government solutions, the strategy states that by 2015, it will be mandatory for citizens to use digital solutions to communicate in writing with the public sector. Once printed forms and letters have been phased out, all citizens will have to use online self-service solutions.

As of 2014, all citizens will have their own digital letter box for correspondence with the public sector. This means that instead of being confined to office hours, citizens will be able to correspond with the public sector when it suits them.

Furthermore, the strategy also focuses on the continued implementation of the "nemSMS" system, which will allow hospitals to send text message reminders to patients about upcoming appointments etc.

Source: Agency for Digitalisation





Local Government Denmark

Local Government Denmark (LGDK) is the association of municipalities in Denmark. The mission of LGDK is to safeguard the common interests of the municipalities, assist the individual municipality with consultancy services and also ensure that the local authorities are provided with relevant, up-to-date information. In addition, LGDK is the employers' association of the municipalities and the negotiation party in relation to local officials' trade unions.

Being responsible for the majority of welfare services in Denmark, the municipalities work with e-solutions on a broad range of welfare areas such as eHealth, e-care and e-learning. To ensure synergy and coordination between the municipal e-initiatives, LGDK's board has adopted a joint municipal digital strategy for 2010–2015. The strategy comprises 32 e-projects covering the work span of Danish municipalities.

LGDK is a partner in major Danish eHealth ventures such as **MedCom** and **sundhed.dk** and is represented on the health minister's national advisory board on eHealth.





MedCom

MedCom was established in 1994 as a publicly financed non-profit joint venture between public authorities, organisations and private companies connected with the Danish health care sector. In 1999, it was decided to make MedCom a permanent organisation with the following purpose:

"MedCom shall contribute to the development, testing, implementation and quality assurance of electronic communication with the purpose of supporting "the good patient flow".

The profile and purpose of MedCom was further sharpened in 2011:

"MedCom is continued with a base in the politically set goals and milestones regarding cross-sectional communication and with an unambiguous role as executing organisation. MedCom solves issues concerning efficient health care delivery and the gradual expansion of the national eHealth infrastructure necessary for secure and connected access to relevant data and messages across regions, municipalities and general practitioners".

MedCom hence focuses on national implementation projects concerning support for the clinical cooperation between general practitioners, public hospitals, private hospitals, specialised treatment, the municipal health sector, laboratories and pharmacies, including telemedicine.

MedCom is owned and financed by the Ministry of Health, Danish Regions and Local Government Denmark.

sundhed,dk

Sundhed.dk

Sundhed.dk supports the digitalisation of the health sector and matches the national and regional milestones and goals set by the Ministry of Health and RSI.

The foundation for sundhed.dk was established in 2003 in order to provide a common digital entry to reliable information about health and the Danish heath system and at the same time create an opportunity to provide health care professionals with access to improved ways of communicating digitally between each other and with patients.

The partners behind sundhed.dk are Danish Regions, the Ministry of Health and Local Government Denmark.

The organisation has an annual budget of approximately 8 million euros and a staff of approx. 40.





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For more information on eHealth in Denmark please visit:

sum.dk ssi.dk regioner.dk kl.dk medcom.dk sundhed.dk



MedCom The Danish Health Data Network 1994-2014

"MedCom plays an important role in the creation of a connected healthcare system in Denmark. MedCom is congratulated, and rightly so, with the anniversary and the good results the organisation has achieved since it was founded 20 years ago."

> Nick Hækkerup Minister for Prevention and Health



Published on the occasion of MedCom's 20 year anniversary 21 May 2014

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Thank you for "Tour de IT"

200 years is a very long time in the IT world. It is a long life for an IT organisation and it is an extremely long period within the world of technology. Therefore, it is not without pride that we, at our 20 year anniversary, can establish that we are still here and that drive and devotion is still alive and well. Even more, we are proud to say: We did it!!!

We took on a huge challenge in the beginning of the 90s when we started realising the vision of a connected health data network where all actors in the Danish healthcare system could exchange the most important messages. Thousands of messages every hour, all year round. It could be compared to our own version of Tour de France in the shape of an IT project of fearprovoking dimensions. As in the real Tour de France, we predicted a lot of steep mountain climbs and tough trials. Not a lot of days freewheeling and not a lot of tail wind. Naturally,

we also hoped for days with small and big wins to keep our spirits up. And we hoped for a helping hand along the way in the shape of users, healthcare professionals and vendors who could, hopefully, see the benefits of the project and the creation of the health data network.

Most of the dream came through. As expected, Tour de IT met massive challenges along the way. However, it was also a journey with small and big wins that showed us that we were on the right track and it gave both MedCom and our partners the will to keep on fighting.

Our many partners have been a key to our success. Passionate people around the country have done much of the hard work when it comes to motivating colleagues or defining proper solutions. Not only in the IT world but also in the general practice, at the hospitals and in the municipalities.



MedCom's project periods are regularly documented - and not just digitally.



The essence of the health data network lies in the collaboration between the partners. This is the secret behind the success. We have a well-functioning network which the whole healthcare sector has embraced and which leaves the rest of Europe and the world speechless.

Have we reached our goals then? Compared to our goals and expectations 20 years ago, we have reached beyond our goals. In many aspects, the health data network anno 2014 exceeds our initial expectations. Still, in this world of health IT, it would be arrogant to claim that our work is done.

20 years ago it was impossible to predict where we would end up. Today, our crystal ball cannot tell us where we will be in 20 years and what the Since 1994, the number of messages based on MedCom standards has increased significantly. The graph shows the total number of messages in average per month.

Danish health data network will look like. So for now, we just establish that we are off to a great start thanks to a lot of hardworking spirits within and outside MedCom.

Henrik Bjerregaard Jensen CEO

A Danish IT success of international proportions

In the past 20 years, Denmark has seen a significant roll-out of IT services within the whole healthcare sector with the hospitals, general practitioners and municipalities leading the way. The daily life of healthcare professionals has changed, millions of Danish kroner have been saved and patients have better insight, more quality and efficiency. All of this has happened quietly without the scandals which often go along large IT projects.

The first ideas to use information technology for communication within the healthcare sector started around 20 years ago. The first step was to exchange prescriptions between a general practitioner on Amager and the local pharmacy. The success of the experiment inspired others. The County of Funen, which it was called at the time, liked the idea and had great ambitions.

IT had long been introduced at many workplaces together with emails and the use of the internet. Why not use information technology within the healthcare sector as well? Attention was directed towards the large number of messages which flow between general practitioners, hospitals and pharmacies. Apart from prescriptions, focus was on referrals from the general practitioner to the hospitals and on discharge letters from hospitals to the general practitioner. The county could have flown solo of course. However, ambitions were bigger already back then. In the long term, a national solution was the goal.

The idea which was born in the County of Funen surfaced at the same time as a group



of enthusiastic users of IT in the healthcare sector gathered to develop some of the ground pillars which enable digital communication today. The ground pillars were and are today a number of standards for key messages which led the way for digital communication to be rolled out following the same recipe all over the country.



Significant digital progresses

Today, 20 years later, even the wildest visions for the healthcare sector from back then have been realised. A long range of the most common messages are now digitalised and mountains of paper forms are no longer necessary. These messages include, for example, prescriptions, discharge letters from the hospitals, referrals from general practitioners to hospitals, admission messages and discharge letters from hospitals to municipalities.

At the same time, information technology is used in areas one could only dream of back in the beginning of the 90s. In hospitals, video conferences are used for translation and the community nurse is able to look up, for example, specialist knowledge about ulcer treatment via telemedicine solutions.

Another significant advance worth noting is that health professionals all over the country are able, at any time, to look up online information about the patient they are



treating, information like medicine, previous treatments etc. The patients are also included. Via the e-health portal, Sundhed.dk, which was established in 2003, all citizens have access to health record information from their general practitioner and visits to hospitals.

A special attention has been given to the health data network which continuously adds more types of users. Involvement of the municipalities was a natural step as they have a significant role in the healthcare sector. The role of the municipalities was strengthened when the structual reform was implemented in 2007. An obvious step was to implement standards for messages about admissions and discharges between hospitals and municipal home care services for citizens who need care at home.

Physiotherapists and medical specialists are also using the health data network. Referrals from the general practitioner to specialists are delivered as an IT message to a kind of "message hotel" where the specialist can collect the referral when the patient contacts them.

From letters to ICT

An added bonus when using information technology is that some procedures, like measuring blood pressure for example, can be done by the patient at home. Similarly, consultations between doctor and patient can be done over a distance. This possibility is especially relevant when distance, to smaller islands for example, makes it difficult and time consuming for the patient to visit the doctor.

This communication is extremely efficient. It eradicates manual working procedures and postal inconveniences and following the digitalised communication, organisations often make adjustments that will result in even bigger gains and savings.

Furthermore, because of the standardised messages the users, doctors and others, are forced to send all required information. They do it via their IT system, and therefore, previous problems with reading incomprehensible handwriting are history. This way, many errors are undoubtedly avoided, for example in situations where the doctor sends a requisition for a lab test and receives the result afterwards.

The messages are automatically integrated into the IT systems of the receiver. When the general practitioner sends a requisition for a lab test with the correct information, the information is automatically integrated into the IT system of the lab.

Whereas communication systems used to focus on exchange of information between the different actors within the healthcare sector, the solution is now to enable a search for relevant information via the health data network – similar to the way you search the internet. An example is the Shared Medication Record, which enables healthcare professionals to search for a patient's current medication etc.

A digital success

Along with the digitalisation, working procedures within most of the healthcare sector have changed. Administrative procedures for general practitioners have become more efficient and the doctor and his or her staff can focus on better patient care. Compared to other countries, the spread of IT at







Since it's foundation, MedCom's role has been to:

"contribute to the development, testing, dissemination and quality assurance of electronic communication and information in the healthcare sector in order to support excellent continuity of care."

With the regional financial agreement for 2011, MedCom's profile was enhanced. The text states that:

"MedCom is continued based on the politically established goals and milestones concerning cross-sector communication and with a particular role as executing organisation".

general practitioners' office today definitely leaves Denmark at first place.

Several factors are keys to the success of this gigantic IT project. First of all, the starting point was of great importance. When the idea of the use of IT in the healthcare sector was born, without even imagining where it would lead, the reality was that no suitable software products were available on the market.



What do you do in this situation? You use the drive which exists within the devoted forces who are able to express their requirements and wishes for a solution. Luckily, a group of engaged general practitioners and hospital staff willingly put a lot of work into the quest. The so-called EDI team was created. At the other side of the table you had the IT experts who knew how to develop the solutions requested by the users. Often, these experts worked for the IT system vendors. More than 60 vendors participated. Consequently, alone the coordination of the development and implementation of IT solutions was a huge challenge.

MedCom was established in 1994 as a project organisation in order to coordinate this work. MedCom was the voice of the users in the collaboration with the IT specialists and was to implement the solutions which were developed.

MedCom worked closely together with the counties and later the regions as well as the municipalities to convince people that energy and effort should be invested in implementing IT solutions. MedCom was in the lucky position that the definition of the IT need and approval of the solutions was grown in the users' own backyards, as it were. It was a bottom-up implementation of IT communication. The users might not have created the solutions but they had defined the needs and approved the end results.

A joint initiative

Another explanation of the success of the health data network is probably that there was no idea of how far this could go from the beginning. In other words, the starting point was not an ambitious and long-term project. Instead, focus has been on small advances – or small victories – and through openness towards the necessity for including new technological and need based possibilities once they present themselves. Telemedicine solutions are examples of this.

Video interpreting and ulcer assessment were spearhead projects within telemedicine. In the 90s, it was unimaginable that these solutions would be part of the health data network. However, MedCom was able and willing to take on the challenge to develop, test and implement these solutions.





Simultaneous with this work, the area of ICT progressed tremendously. The internet has become a natural part of people's life. Video communication is a reality and most people are comfortable with online communication. This development has probably helped MedCom in deploying IT solutions because there has been a general understanding that of course the health care sector should be able to take advantage of the new technological advances.



Dessimination of solutions which improve efficiency, service levels and quality for users in the healthcare sector have received political appreciation and support. Political decisions that national solutions should be developed within this field to enable seamless communication between the different parts of the country, naturally has made MedCom's work with deploying these solutions easier.

International attention

From being a two-year based project organisation, MedCom became a permanent organisation in 1999. This of course in the light of that MedCom had proved its worth.

MedCom's work also has an international dimension. Early on, it was clear that collaboration with international partners would benefit all partners in the work towards better IT solutions within the healthcare sector. Over the years, Denmark and MedCom have been very active on the international scene and has strongly contributed to the success of numerous international projects. Inspiration and knowledge sharing has naturally also benefited the Danish development of IT solutions.

MedCom has received great international recognition, also from the European Commission. An honour which should be shared with the hundreds of enthusiastic enthusiasts from the regions, municipalities, GPs and IT vendors who have been an essential and integrated part of the MedCom cooperation through the years.

The distinguished state of the health data network today has almost gone unnoticed. The media has found no interest in the network, perhaps this is due to the fact that bad investments and scandals have been avoided long the way. In that sense, the Danish society has, in a period of 20 years, created a unique IT success.



The Danish Health Data Network year by year

Pioneers lay the first tracks

The SEDI group – the EDI group 1990 of the National Board of Health starts coordinating projects and standards for the most important messages - discharge summaries, lab reports and prescriptions.

Electronic prescription from the general practitioner to the pharmacy

The Amager project tests the 1990 electronic prescription. Today, all pharmacies and doctors use electronic prescriptions.

MedCom – the Danish Health **Data Network**

The County of Funen suggests to 1992 establish a nationwide project with the purpose of developing and implementing standards for communication between GP's and hospitals.

The majority approves

More than 60% of the GPs has 1992 implemented electronic medical records in general practitioners' offices. Consequently, their normal practice has changed completely. However, the systems cannot intercommunicate.

Working together to create the first standards

1994 In the first MedCom project, 37 vendors of hospital systems and systems for general practitioners participate in the development of EDI standards for the most

important messages.

During MedCom 2, the municipalities take their first steps into cyberspace

Several municipalities initiate 1997 pilot projects within basis communication with doctors, pharmacies and hospitals. The first telemedicine projects are initiated.

Pioneers test the idea of cross regional cooperation

Two counties in Jutland started a 2000 SUP project with the purpose of enabling communication between hospital departments' electronic health records and establishing one common database in which the health information could be searched and retrieved.

Communication about the good messages

2000-01 The "Good EDI letter" was defined by MedCom. Around 60 vendors were involved in the work.

Citizens' access to their own prescriptions

The Danish Health and 2003 Medicines Authority set up the prescription server where all prescriptions are stored. This way, all citizens have access to their own prescription data and pharmacies have access to information about medication dispensed at other pharmacies.



sundhed.dk - the Danish e-Health Portal

Suggestion to creating a com-2003 mon public internet portal for health data. The internet based health data network is launched.

MedCom takes over the responsibility to deploy access to health record data

2004 MedCom becomes project manager for the e-Journal project which supports the refinement and dissemination of the use of the health record database.

EDI becomes XML

2005 XML-standards are developed as a supplement to the old EDI standards.



NSI – the National Board of e-Health

2006 The national coordination of ehealth is strengthened with the birth of the organisation Digital Health in Denmark which changes name to the National Board of e-Health after three years. NSI is responsible for national strategy and coordination.

Wider access to journal data for citizens

2007 Under the e-journal project, citi-

zens in one county and the GPs in the whole country get access to journal data using digital signature via Sundhed.dk

The first healthcare agreements focus on e-communication

2007 The counties are dissolved and municipalities signed a healthcare agreement with the new regions about cross sector communication for admissions, discharges and rehabilitation.

Telemedicine is deployed nationwide

2009

The dissemination of video interpretation is initiated by the Danish Agency for Digitalisation as the first telemedicine implementation project. At the same time, a cross-sectorial national video infrastructure is established.



regionernes sundheds-it

RSI – Danish Regions Health IT

2010 Danish Regions strengthen their coordination and adopt 15 indicators which all regions must work towards.

European record

2011 Close to a 100% of theGPs has IT systems which can exchange information with the other parts of the healthcare sector. IT is part of most of the general practitioners' workflows. An EU study of the use of IT in the GP offices places Denmark at first place.

Communication is constantly deployed and expanded

2014 Th

The municipalities are important actors on the health data network when it comes to communication with hospitals, pharmacies and the GPs. Communication includes areas of prevention, rehabilitation, home care as well as the paediatric area. Henceforward, communication will be extended to cover the psychiatric and social area as well, and a new generation of healthcare agreements are on their way.

Telemedicine

2014

The national action plan for extensive deployment of telemedicine focuses on video conferencing, image sharing and home monitoring.



The Shared Medication Record

2014

The vision of online access to patients' current medicine record is currently being implemented. Within the next couple of years, all GPs, hospitals and municipalities will use the same shared medication record.

Ready for test and certification

2014

MedCom is ready with test and certification tools which are used by vendors, also as self-service. New standards are underway in the form of HL7-IHE profiles.

The history of the ground pillars of the Health Data Network



EDI becomes XML

2005 XML standards are being developed as a supplement to the old EDI standards.



In order to support the IT suppliers' work on XML-EDIFACT conversion, MedCom has developed a web based converter which is available via www.medcom.dk or directly via the address http://web.health-telematics.dk/ xmledi

Communication about the good messages

The Good EDI

In the consolidation project, documentation in the form of "the Good EDI letter" for all used messages have been created. www.medcom.dk includes:

- Syntax and communication rules The Good discharge letter 00
- The Good correspondence
- The Good referral 03
- The Good KKA/KIA lab report
- The Good pathology report
- 06
- The Good Microbiology report The Good KKA/KIA lab requisition
- 08
- The Good pathology requisition 09
- The Good analysis register The Good the good health insurance
- 12 14 The Good municipality reports
- The Good prescription The Good CONTRL
- The Good physiotherapy referral
- The Good podiatry referral Test guides Test protocol for MEDREQ, MEDREF, MEDRUC Test examples



2000-01



Collaboration on the first standards

About 37 vendors of hospital systems 1994 and systems for the GP offices were involved in the development of EDI standards for the most important messages.

Discharge summaries and lab reports

Two cornerstones in the foundation of the Health Data Network

Implementation of modern e-health solutions is an important part of the digitalisation of the whole public sector. As a token of appreciation, MedCom was awarded the Danish Digitalisation Prize 2007. The prize is found to promote IT projects and visions which are of value to citizens and the com-



Photo: Torben Nielsen



Alex Tran hoto:

Focus on deployment

The standards are devel-1997 oped and in MedCom 2 the standards are disseminated. Discharge letters and lab reports become electronic all over the county as a result of more than 200 sub-projects with focus on these types of messages in the counties.



Commendable results

300

MedCom receives the Danish and European 2007 e-health prize. A big part of the explanation is found in the successful deployment of discharge summaries and lab reports.



Development of standards for the most important messages

MedCom is founded as a 1994 two-year project with focus on development of standards for the most frequently used messages between GPs and hospitals, namely discharge letters and lab reports.

IT has changed the everyday practice in the GP office



World record

2011

100% of the GPs has IT, and IT is part of almost all daily practices and processes of the general practitioner. An international study places Denmark at first place.

The majority approves

1993 More than 60% of the GPs has implemented IT and, consequently, the daily practice in the GP offices has changed completely. Work processes are made more efficient. 120 forms have been reduced to a handful of electronic forms for example.



Local EDI projects

1992

Lab reports, discharge letters, reimbursement claims, x-ray reports and prescriptions are sent electronically in local EDI projects, KPLL – Odder – Fyncom.



Enthusiasts lay down the first tracks

1991 The SEDI group – the coordination group of the National Board of Health, a group of enthusiasts from the primary and secondary sector, starts developing national standards for the most important messages – discharge summaries, lab reports and prescriptions.

Tentative beginnings



Prescriptions are exchanged as the first electronic message.

Naturally, the municipalities are also joining

Photo: Benat Olof Olsson/Billedhuset

Communication is disseminated and is continuously expanded

2014 All municipalities have electronic communication within several social and healthcare areas. Communication includes areas of prevention, rehabilitation, home care as well as the paediatric area. Currently, communication are being extended to cover the psychiatric and social areas as well, and a new generation of health agreements are on their way.

The first healthcare agreements focus on e-communication

2007 The counties are dissolved and municipalities signed a healthcare agreement with the regions about cross regional communication for admissions, discharges and rehabilitation. In October 2007, 65 municipalities used electronic communication: The North Denmark Region: 7 municipalities, The Central Denmark Region: 7 municipalities, Region Zealand: 9 municipalities, Region of Southern Denmark: 18 municipalities and Capital Region: 24 municipalities.

The municipalities take their first steps into cyberspace

1997 Several municipalities initiate pilot projects about basic communication with hospitals as well as correspondence and renewal of prescriptions with GPs and pharmacies.

The e-Journal

Health records are shared knowledge



Two common national databases, the e- and p-journal with data from health records from the public hospitals and the general practices respectively are a reality today.

Clinicians and citizens have access to all this information. E- and p-journal are part of the Sundhedsjournalen (health journal) which, among other things, also contains data from lab databases and the Shared Medication Record.

Du har direkte adgang til din patients E-Journal

system for at gå direkte til patientens E-Journal på sundhed

medc_m



500000

Access to data for the GPs and citizens

2007 The project changes name to e-Journal and citizens in one county and the GPs in the whole country are granted access to health record data via Sundhed.dk using digital signature.

MedCom enters the scene

2004 MedCom becomes project manager for the further development and deployment of the use of the database with health record data.





A very large proportion of the paper records at the hospitals consisted of lab reports, lab requisitions, referrals, discharge letters, reports and correspondence with other departments, other hospitals and the primary sector.

Pioneers test the good idea

2000 Three counties in Jutland started a project with the purpose of enabling communication between hospital departments' electronic health records and establishing one common database in which the health record information could be searched for and retrieved.

Online information about medicine

A future with access to a shared and complete overview of citizens' current medication

ælles Medicinkort En fremtid med adgang til et fælles og samlet overblik over borgernes aktuelle medicinering

The Shared Medication Record

2014 Online access to patients' current medication is now being implemented. Within the next couple of years, all GPs, hospitals and municipalities will use the same shared medication record.

Fælles Medicinkor så kører

– nu også i kommunerne 2014/2015

Citizens' access to own prescriptions

The Danish Health and Medicines 2006 Authority sets up the prescription server where all prescriptions are stored. This way, all citizens have access to their own prescription data and pharmacies have access to information about medication dispensed at other pharmacies.

FÆLLES MEDICINKOR



Electronic prescription from the general practitioner to the pharmacy

The Amager project tested the electronic <u>1991</u> prescription. MedCom was in charge of the dissemination. Today, all pharmacies and doctors use electronic prescriptions.

Time for Face-time!!!

After 16 years of preparations, the Danish healthcare sector is ready for telemedicine cooperation via video conference, exchange of images and collection of data from the home of the citizen.

We face a whole new generation of digital health communication which directly involves the patient in the cooperation between the different actors within the healthcare system. The national strategy for digitalisation of the healthcare sector from 2013 makes telemedicine a mainstream approach within the whole public sector.

Today, MedCom plays a central role as an executing organization in relation to national dissemination of cross-sector telemedicine solutions, including securing the technical infrastructure supporting – amongst others – video conferencing and data collection in the citizen's home.



2012 The government, Danish Regions and Local Government Denmark implement the telemedicine visions in a shared action plan which highlights five concrete telemedicine concepts which, through clinical use, will mature enough to be deployed on a national scale.

Doctor

?

Patient



From local to national

2009 With the funding from the Danish Agency for Digitalisation, interpretation via video conferencing will be the first telemedicine concept which will go from local project to nationwide scale up within all hospitals.







Possibilities are endless. You only have to use them

2001 The Ministry of Health conducted a survey which concluded that the potential for telemedicine solutions is enormous. However, we have a long way to go.

The first step into the future

90'erne By the end of the 90s, MedCom started the first national projects on image transmission. Focus was on dermatology, radiology and pathology. Through the 00s, video conferencing between different parts of the health care sector gave the first technical experiences and, in the beginning, home monitoring of COPD patients was tested in international projects.

"MedCom is continued based on the politically established goals and milestones concerning cross-sector communication and with a particular role as executing organisation."

The regional financial agreement for 2011







Country Brief: Finland

Authors: P. Doupi, E. Renko, P. Hämäläinen, M. Mäkelä, S. Giest, J. Dumortier

October 2010





European Commission, DG Information Society and Media, ICT for Health Unit




About the eHealth Strategies study

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

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Reviewer

Anne Kallio

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Executive summary

Finland's eHealth roadmap¹ from 2007 is a follow-up to the *Strategy for utilising information technology in the field of social welfare and healthcare in Finland*, which was launched in 1996. Its underlying principle is the development of seamless service chains, which requires the introduction of new technology, new types of information system architectures, and better compatibility between information systems. It refers to the EU eHealth Action Plan (2004), encompasses the assessment of the current eHealth status, implementation strategies, standards as well as infrastructural aspects and possible cross-border cooperation.

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

In 2002, the Finnish Government decided to introduce nationwide electronic patient records by the end of 2007² and the National Health Project Program was launched, including an electronic patient record project. Previously every service provider had its own patient record system which was not usually interoperable. Then, in December 2006, a national EHR archive (eArchive) was introduced in order to enable access and exchange of patient information across organisations. To ensure this all EHR systems joining the national eArchive use a predefined structure.

The Finnish eArchiving solution to EHR interoperability is not a Patient Summary solution. The records of each healthcare provider are archived and accessed separately. It is likely that a Patient Summary view, combining data from the different EHRs, will be developed within the eArchiving service, although this has not yet been specified.

After a series of ePrescription pilots, starting in 2002, through which refinement took place, a final phase of ePrescription pilots started again in May 2010. Once ePrescription is fully operational, doctors can issue and sign ePrescriptions electronically as well as store them in the centralised system (Prescription Center).

A nationally elected set of standards has been defined, based on international standards such as HL7, CDAR2, ISO/OID or DICOM. But still, critics say that common standards are too few in Finland. On a different aspect of standards the project SAINI proposes to standardise technical solutions and electronic services for citizens.

A wide range of telemedicine applications has been implemented and runs as a regular service in Finland including telemonitoring, telediagnosis, teleconsultation and telelaborotory. Generally, telemedicine in Finland is regarded as a positive solution for overcoming geographical distances.

¹ Ministry of Social Affairs and Health 2007

² Decision-in-Principle by the Council of State on securing the future of health care, issued in April 2002



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1 Introduction to the report

1.1 Motivation of the eHealth Strategies study

Following the *Communication* of the European Commission (EC) on "eHealth – making healthcare better for European citizens: An action plan for a European eHealth Area".³ Member States of the European Union (EU) have committed themselves to develop and issue national roadmaps – national strategies and plans for the deployment of eHealth applications addressing policy actions identified in the European eHealth Action Plan.

The 2004 eHealth Action Plan required the Commission to regularly monitor the state of the art in deployment of eHealth, the progress made in agreeing on and updating national eHealth Roadmaps, and to facilitate the exchange of good practices. Furthermore, in December 2006 the EU Competitiveness Council agreed to launch the *Lead Market Initiative*⁴ as a new policy approach aiming at the creation of markets with high economic and social value, in which European companies could develop a globally leading role. Following this impetus, the Roadmap for implementation of the "eHealth Task Force Lead Market Initiative" also identified better coordination and exchange of good practices in eHealth as a way to reduce market fragmentation and lack of interoperability.⁵

On the more specific aspects of electronic health record (EHR) systems, the recent *EC Recommendation on cross-border interoperability of electronic health record systems*⁶ notes under "Monitoring and Evaluation", that "in order to ensure monitoring and evaluation of cross-border interoperability of electronic health record systems, Member States should: consider the possibilities for setting up a monitoring observatory for interoperability of electronic health record systems in the Community to monitor, benchmark and assess progress on technical and semantic interoperability for successful implementation of electronic health record systems." The present study certainly is a contribution to monitoring the progress made in establishing national/regional EHR systems in Member States. It also provides analytical information and support to current efforts by the European Large Scale Pilot (LSP) on cross-border Patient Summary and ePrescription services, the epSOS - European patients Smart Open Services - project.⁷ With the involvement of almost all Member States, its goal is to define and implement a European wide standard for such applications at the interface between national health systems.

³ European Commission 2004

⁴ European Commission 2007

⁵ European Communities 2007

⁶ European Commission 2008

⁷ European Patients Smart and Open Services (epSOS)



Earlier, in line with the requirement to "regularly monitor the state of the art in deployment of eHealth", the EC already funded a first project to map national eHealth strategies – the eHealth ERA "Towards the establishment of a European eHealth Research Area" (FP6 Coordination Action)⁸ - and a project on "Good eHealth: Study on the exchange of good practices in eHealth"⁹ mapping good practices in Europe - both of which provided valuable input to the present *eHealth Strategies* work and its reports. Member States' representatives and eHealth stakeholders, e.g. in the context of the *i2010 Subgroup on eHealth* and the annual European High Level eHealth Conferences have underlined the importance of this work and the need to maintain it updated to continue to benefit from it.

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

1.2 Survey methodology

After developing an overall conceptual approach and establishing a comprehensive analytical framework, national level information was collected through a long-standing Europe-wide network of national correspondents commanding an impressive experience in such work. In addition, a handbook containing definitions of key concepts was distributed among the correspondents to guarantee a certain consistency in reporting. For Finland, the National Institute for Health and Welfare¹⁰ (THL) provided information on policy contexts and situations, policies and initiatives and examples for specific applications. THL generates information and know-how in the field of welfare and health and forwards them to decision-makers and other actors in the field. The Institute is overseen by the Finnish Ministry of Social Affairs and Health.

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

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

⁸ eHealth Priorities and Strategies in European Countries 2007

⁹ European Commission; Information Society and Media Directorate-General 2009

¹⁰ National Institute for Health and Welfare



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

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

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

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

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

1.3 Outline

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



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

The report finishes with a short outlook.

2 Healthcare system setting

2.1 Country introduction

The Finnish state is composed of three administrative levels: the central level made up of the national ministries and central authorities; the regional level - which until the end of 2009 consisted of 6 provinces (Åland, South Finland, Eastern Finland, Western Finland, Lapland, and Oulu) and as of 1.1.2010 is represented by the Regional State Administrative Agency and the Centre for Economic Development, Transport and the Environment¹¹, and the municipal level, which has a high degree of sovereign power for policy-making, especially in the fields of healthcare and social services. Finland has a very low density of population and an economy which is heavily concentrated in the three big agglomerations around Helsinki, Tampere and Turku, all of which are in the south of the country. Most other parts of the country have somewhat lower rates of income and tend to suffer from emigration.

In general, there are three different healthcare systems in Finland: municipal healthcare, private healthcare and occupational healthcare. The systems have significant differences, as for example in the scope of the services provided, user-fees and waiting times.¹²

In its institutional structure, financing and goals, the Finnish healthcare system is closest to those of other Nordic countries and the UK, in that it covers the whole population and its services are mainly produced by the public sector and financed through general taxation. The Finnish healthcare system is one of the most

¹ Aluehallintovirasto [Regional Government Agency] , Elinkeino-, liikenne- ja

ympäristökeskuksia [Centres for Economic Development, Transport and the Environment]

¹² Vuorenkoski, Mladovsky et al. 2008



decentralised in the world. Even the smallest of the (presently, March 2010) 342¹³ municipalities (local government authorities) are responsible for arranging and taking financial responsibility for a whole range of 'municipal health services'. The population of municipalities (outside of Åland Islands) currently varies from 804 inhabitants to over 580 000. The mean size is about 16 000 inhabitants and the median about 5 800 inhabitants. In order to address the challenge of ensuring the provision of basic municipal services in the future, a major project of "Restructuring municipal services" (PARAS project, in Finnish) has been in progress since 2007¹⁴. In the new setting, organisational responsibility for primary healthcare, as well as certain welfare services closely related to health services, will reside with organisations covering at least 20000 inhabitants. The target date for completion of the process is 2012.

From an international perspective another unique characteristic of the system is the existence of a second public finance scheme (the National Health Insurance – NHI-scheme), which reimburses partly the same services as the first, but also services which are provided by the private sector. In addition to subsidising the use of specific private health services, the NHI scheme also finances occupational and student health services and outpatient medicines.¹⁵

The box below summarises the key facts about the Finnish healthcare system:

Key facts about the Finnish healthcare system:¹⁶

Life expectancy at birth: 79.7 years

Healthcare Expenditure as % of GDP: 8.2% (OECD 2007)

WHO Ranking of Healthcare systems: rank 31

Public sector healthcare expenditure as % of total healthcare expenditure: 75% (OECD 2007)

¹³ Kuntaliitosselvitykset ja tulevat kuntaliitokset [Reports on merging of municipalities and forthcoming mergers]

¹⁴ Vuorenkoski 2008

¹⁵ Häkkinen 2005

¹⁶ Data from World Health Organization 2000; World Health Organization 2009

2.2 Healthcare governance¹⁷

Decision making bodies, responsibilities, sharing of power

The Finnish Government decides on general national strategies and priorities and proposes bills to be discussed by Parliament. Healthcare policy is primarily the field of the MSAH¹⁸. The MSAH directs and guides the development and policies of social protection, social welfare and healthcare. It defines the main course of social and health policy, prepares legislation and key reforms and steers their implementation, and handles the necessary links with the political decision-making process. The general aims of social welfare and healthcare and the measures that will be taken in order to fulfil these aims are adopted in the National Development Programme for Social and Welfare (previously Target and Action Plan for Social Welfare and Health Care) that is drawn up for the whole period of office of each Government, normally for four years.

Municipalities (i.e. the local authorities) have, by law, the main responsibility for ensuring basic services such as education (except university education) and social and health services are provided for their inhabitants. Municipalities have the right to levy income and real estate taxes. They also receive a subsidy from the state to enable them to organise the services they are obliged to provide. In addition to the state subsidy for healthcare, they receive state subsidies for social services and schooling. The state subsidy to municipal social welfare and healthcare expenditure is determined by the population, age structure and morbidity in the municipality plus a number of other computational factors. The subsidies constitute about 25% to 30% of municipal spending on health services.

The main decision-making power in municipalities lies with the municipal council, which is elected every four years by the inhabitants of the municipality. There are variations in detail and emphasis in the decision-making process in municipalities. The general trend has been towards delegating power from municipal councils to the various committees and leading officials. Decisions on the planning and organisation of healthcare are made by the health committee, the municipal council and the municipal executive board. Here again there are variations. The leading persons of the municipal health centres are often also included in the planning and organisation of health services. To improve the coordination of social and health services, the traditionally separate health boards and social welfare and services boards have been merged into a single board in most municipalities.

In practice, the hospital district administration (see below) wields power over the organisation of specialist hospital services within municipal healthcare, even if the municipality formally procures the services. Specific legislation supports this power.

¹⁷ Vuorenkoski, Mladovsky et al. 2008

¹⁸ Ministry of Social Affairs and Health



There is a further administrative level between the state and municipalities, the province which has also undergone significant restructuring as of 1.1.2010 (see earlier in this section).

Healthcare service providers

Primary health services provided by municipalities are defined in the Primary Health Care Act¹⁹. The act states that every municipality must have a health centre which provides primary health services. Municipalities can either provide these services independently or join with neighbouring municipalities in joint municipal boards which set up a joint health centre (a municipal federation-maintained health centre).

In larger cities, the services of health centres are provided through several health stations located in different parts of the city (for example Helsinki has 29 health stations around the city). Municipalities can also purchase some primary health services from private providers or hospital districts. Health centres provide occupational healthcare services for those employers who choose to purchase these services from health centres.

Specialised care funded by municipalities is mainly provided by hospitals maintained by the hospital districts and regulated by the Act on Specialised Medical Care²⁰. Currently, the Act divides the country into 20 hospital districts (excluding Åland Islands). Each municipality must be a member of one hospital district (the number of member municipalities varies from 6 to 58).

The hospital districts organise and provide specialist medical services for the population of their member municipalities. The hospital districts are federations of municipalities. These federations are separate from federations maintaining health centres. However, recently there have been local reforms to integrate these two organisations.

Each hospital district has a central hospital, five of which are university-level teaching hospitals. Hospital districts are managed and funded by the member municipalities. The catchment population of hospital districts varies from 65.000 to 1.4 million inhabitants. A referral from a licensed physician is needed for access to medical care provided at the hospital districts. Life-threatening emergencies are of course exempt from this requirement. The referring physician does not have to work in the municipal health centre. Referrals from private practice, occupational health services or other clinics in the specialist hospital are equally honoured.

Nongovernmental organisations (NGOs) and foundations are also active in the healthcare sector. These organisations provide a very broad spectrum of services. Municipalities and hospital districts can purchase services from these providers. These organisations can receive subsidies from the Finnish Slot Machine

¹⁹ Act on Primary Healthcare 66/72

²⁰ Act on Specialised Medical Care 1062/89



Association (which has a monopoly on gambling in Finland and is governed by the state) for providing healthcare services.

The aforementioned structure of healthcare service provision is expected to undergo major changes with the upcoming introduction of the completely new Health Care Act (a merge of the Primary Health Care Act of 1972 and the Act on Specialized Medical Care of 1989)²¹ The proposal for the new Act is expected to be brought to Parliament by the end of April 2010. It is expected that it will be a major milestone in the development of the Finnish healthcare system and it will create a good platform for future development of the municipal healthcare system²².

The figure below summarises important features of Finnish healthcare organisation:

Political/administrative unit responsible for primary healthcare	Municipal responsibility.
Consumer Choice	Mixed: area or list patient organised.
Financing	Mainly tax-based financing.
Public or private providers	Mixed: both private GP practices and publicly employed doctors.
Gatekeeping function of the GP	GP gatekeeping function in the public sector, but patients have direct access to specialists and hospitals in the private sector.
Integrating health: initiatives for coordination	Joint team work; developmental projects for collaboration, national healthcare plans; local and regional coordination groups/boards.

Figure 1: Important features of primary healthcare organisation in Finland²³

²¹ Vuorenkoski 2008

²² More information available at: <u>http://www.stm.fi/vireilla/lainsaadantohankkeet/sosiaali_ja_terveydenhuolto</u> (only in Finish)

²³ Krasnik and Paulsen 2009

2.3 Recent reforms and priorities of health system/public health

Earlier reforms in the health and social care systems²⁴

The most important reform in Finnish healthcare in the last decade occurred in early 1993 as part of a reform of the entire state subsidy system. The main objective of the reform was to define the relationship between the state and the municipalities rather than to directly introduce major changes in health policy priorities. An essential element of the reform was the revision of the grounds for determining state subsidies to municipalities for health services. Under the old system, state subsidies to municipalities or federations of municipalities (producers) were ear-marked and related to real costs. Under the reformed system, state subsidies for running costs in health services provided by municipalities are non-earmarked lump-sum grants, which are calculated prospectively by using a specific need-based capitation formula.

The aim of the reform was to reduce central government control and to increase local freedom in the provision of services. This made it possible for municipalities to adopt a more active role as a purchaser instead of acting in the mainly producer's role as previously. Particularly in the field of specialist hospital care, the reform meant that the system changed somewhat from a public integrated model to a public contract model.

Furthermore, an independent centre for HTA²⁵, known as Finohta, was established in 1995 within STAKES²⁶. The centre's main objective is to promote evidence-based medicine and to improve the effectiveness and cost-effectiveness of care (mainly non-drug diagnostic or treatment methods). Finohta coordinates HTA research, disseminates information and gives methodological and financial support to research projects aiming at evaluating the clinical effectiveness or cost-effectiveness of a given health technology. The majority of the funding for Finohta comes from the state. As a result of the decisions that were made based on the National Project to Ensure the Future of Health Care, the annual state funding of Finohta was doubled from 1.1 million to 2.2 million euros between 2004 and 2007.

In 2007, the Government initiated a new four-year multi-sectoral Government programme entitled the "policy programme for health promotion". The objectives of the health-promotion programme are to improve the general state of health of the population and to reduce health inequalities. The policy programme continues with efforts to promote health and prevent health hazards beyond conventional administrative boundaries. Issues to be addressed in the context of the programme

²⁴ Vuorenkoski, Mladovsky et al. 2008

²⁵ Health Technology Assessment

²⁶ STAKES and the National Public Health Institute (KTL) were merged in 2008 and are now known under the name of "National Institute for Health and Welfare" (THL).



will include developing measures to promote health and related legislation, promote the well-being of children and youth, improve the health, functional capacity and work-place welfare of people of working age, promote the health and functional capacity of older people, assign responsibility for preventive efforts and allocate related resources, stress the importance of physical activity and culture for wellbeing and increase the health of the environment.

2.4 ICT use among general practitioners

This section provides a brief overview of relevant ICT related infrastructure and services data. It draws on earlier studies commissioned by the EC, notably the Indicators eHealth Study . Although the results of this study date from 2007 and may therefore not reflect latest changes, a more recent pan-European survey is not available²⁷.

In terms of infrastructure 100% of GP practices in Finland are equipped with one or more PCs. The same share, that is 100% of the practices, disposes of an Internet connection. In Finland, broadband represents the most common form of access to the Internet with 93% of GP practices resorting to broadband connections.

The storage of electronic medical patient data is universal in Finland as 100% of the GP practices register at least one type of patient data.

In Finland, the use of electronic networks for the transmission of medical patient data is well established and wide-spread. 90% of the GP practices use networks to receive laboratory results and 55% exchange data with other healthcare providers.

The exchange of administrative data is averagely well developed. 21% of the Finnish GPs use networks to exchange administrative patient data with other carers.²⁸

Nationwide ePrescribing has not yet arrived in Finland.

²⁷ ICT and eHealth use among General Practitioners in Europe 2007

²⁸ In other studies (eHealth of Finland 2008), 77% of Finnish healthcare centres reported exchanging eReferrals and eDischarge letters (so both administrative and clinical data) with other healthcare providers. The percentage was 45% in 2005. This discrepancy can be explained by methodological differences in the two studies. Annex I below provides a list of the indicators used for the data presented here.





Figure 2²⁹: eHealth use by GPs in Finland

3 eHealth strategies survey results

The following sections present the results of the eHealth strategies online survey. In a first section, the eHealth policy actions undertaken in Finland are presented. This is followed by a presentation of administrative and organisational measures taken. Section 3.2 presents results on key eHealth applications. Section 3.3 focuses on the technical side of eHealth, namely the role of patient and healthcare provider identifiers and the role of eCards. Legal and regulatory facilitators as well as financing and reimbursement issues are presented in the following chapters, 3.4 and 3.5. The report concludes with evaluation activities (3.6) in the country and an outlook (4.).

²⁹ The notion of "compound indicator" designates an indicator build from a set of other indicators/survey questions regarding the same topic. The compound indicator reflects an average calculated from different values. (see Annex) The final results of the study on eHealth Indicators is available at <u>www.ehealth-indicators.eu</u>.



3.1 eHealth policy action

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

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

3.1.1 Current strategy/roadmap30

Finland's eHealth roadmap31 from 2007 is a follow-up to a national strategy called "Strategy for utilising information technology in the field of social welfare and healthcare in Finland", which was launched by the Ministry of Social Affairs and Health in 1996. Its underlying principle is the development of 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.

From 1996 onwards, the Ministry of Social Affairs and Health has consistently pursued the creation of an implementation chain for the deployment of eHealth with four important landmarks, summarised in the box below:

Finland

³⁰ Tekes; Ministry of Social Affairs and Health 2007

³¹ Ministry of Social Affairs and Health 2007



Important landmarks in Finnish eHealth policy development

1996: Strategy for utilising information technology in the field of social welfare and healthcare in Finland

1998: Update of the strategy, placing emphasis on several issues, e.g. digital patients records, nationwide interoperability or privacy protection

2002: Decision-in-Principle by the Council of State for the introduction of nationwide patient records

2007: "eHealth Roadmap for Finland" is published by the Ministry of Social Affairs and Health

After the first strategy from <u>1996</u>was built around the principle of citizen-centred, seamless service structures an update followed in <u>1998</u>, placing emphasis on the following targets:

- 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.

Following the Government Resolution from 2002, a national electronic patient record system development project (2003-2007) was set up as part of the National Health Programme. Implementation was organised through the working group steering the introduction of electronic patient records appointed by the Ministry of Social Affairs and Health. This working group outlined a national implementation strategy for electronic patient records, which was published in 2004. In a follow-up report (2005), the principal requirements to which all electronic patient record systems should conform were published.

The purpose of the current Finnish roadmap from <u>2007</u>, which directly refers to the EU eHealth Action Plan (2004), is to summarise the major national policy achievements during the past ten years and to chart future challenges, and also to present Finland's strategic objectives with regard to the European targets set by the Commission. The roadmap was developed by a working group appointed by the Ministry of Social Affairs and Health (STM). In sum, it encompasses the assessment of the current eHealth status, implementation strategies, standards as well as infrastructural aspects and possible cross-border cooperation.

Furthermore, different legal acts were established within recent years. These are shortly named here and further explained in section 3.4 on "legal and regulatory facilitators". Acts, which are connected to the establishment of an eHealth structure, are the following:

Legal acts concerning eHealth development in Finland
Personal Data Act from 1999
Act on Experiments with Seamless Service Chains in Social Welfare and



Care Services from 2000

Decree on the Storing of Patient Data from 2001

Regulation on the Use of Electronic Social and Healthcare Client and Patient Information from 2007, also called the "Client Data Act"

Legislation on the Use of ePrescription from 2007

Documents from other domains include the e-Welfare programme (2005). It is part of a new information society programme and is aiming to develop ICT for social services. TEKES, the Finnish Funding Agency for Technology and Innovation³² (formerly the National Technology Agency of Finland) managed the FinnWell - Future Healthcare Programme that lasted five years (2004–2009) and included a healthcare development programme, while since 2009 it has enabled the establishment and operations of the Strategic Centre for Health and Well-being (SalWe)³³.

Figure 3: Finnish policy documents related to eHealth



© empirica 2009

³³ SalWe 2010

³² Tekes

eHealth

3.2 Administrative and organisational structure³⁴

Finland

The Ministry of Social Affairs and Health has the leading role in eHealth policy. The same Ministry also has the responsibility to develop the regulatory framework and the legislation for the management of personal digitalised health information. Municipalities and their jointly owned hospital districts have, by law, a strong decision making power in all health policy matters including eHealth. The Prime Minister's office established an Information Society Programme in 2003-2007, which has been followed by the Ubiguitous Information Society Action Programme 2008 -2011. The Ministry of Justice, through the Data Ombudsman Office has established a permanent security and privacy protection group for healthcare (TELLU). The State IT-organisation, which is financed and guided by the Ministry of the Interior, is co-ordinating national development in the field of eGovernment. The Ministry of Transport and Communications has the leading role in elnclusion development. The Ministry of Trade and Industry is financing the Finnish Funding Agency for Technology Development and Innovation (TEKES), which, in turn, is funding R&D programs. The Ministry of Education participates also in the Information Society Programme.³⁴ Recently (in summer-autumn 2009), the Ministry of Finance has launched in the framework of the program on eServices and eDemocracy (SADe program) the preparation of an integrated platform for the provision of health and social care services to citizens (as one of the targeted activity areas).

With regard to national level eHealth implementation the major stakeholders are the following: ³⁵

- the Ministry of Social Affairs and Health, which in addition to its policy role has the responsibility for the national architecture, semantic and technical definitions (user cases for EHR-programs), certification of EHR-systems, healthcare units and central infrastructure;
- KELA (The Social Insurance Institution of Finland), that has the responsibility of the central infrastructure, i.e. the eArchive and Prescription center, acts as the register keeper of the Prescription centre and manages the development of the eView (application for citizens' access to the eArchive);
- VALVIRA (National Supervisory Authority for Welfare and Health), that acts as the authentication of healthcare professionals. Its role as national verifier for healthcare professionals through smart cards for strong authentication and electronic signature will in 2010 be transferred to the Population Register Centre.;
- **THL** (National Institute for Health and Welfare), that maintains the national code center and contributes to the further development of structured EHR systems.

³⁴ Kallio 2008

³⁵ European Patients Smart and Open Services (epSOS)



At the local level, the main eHealth implementation stakeholders are;

KUNTALIITTO (Kommunförbundet, League of Local Authorities) for organizing the co-operation of clusters, co-operation communities (7 in total) for making definitions and ordering changes to EHR-systems; **KunTo**, the Municipal Project Coordination Office providing guidance and assisting local implementations, the **Hospital Districts**, who manage distribution of smart cards, are the regional actors in local and regional implementations and finance necessary changes to EHR-systems, and **municipalities** for the local implementations and the financing of changes to EHR-systems.

Other important stakeholder, particularly in the context of the development and implementation of KanTa - the National Archive of Health Information (see section 3.2.1 for further details) are healthcare providers, both public and private, pharmacies, subcontractors for the EHR systems and network services, as well as the Association of Finnish Pharmacies and the Finnish Medical Association.

Finally, there are three more relevant actors in Finnish eHealth activities: 1) The National Institute for Health and Welfare – Unit for Information Structures and Classifications (former Unit for eHealth and eWelfare); 2) The Finnish Society of Telemedicine and eHealth (FSTeH) and 3) The Finnish Social and Health Informatics Association (FinnSHIA).

The function of the THL Unit for Information Structures and Classifications is, in addition to maintaining the national coding systems and terminologies within healthcare and social services, to engage in research and development and provide expertise in information society issues in the social and health sector. The use of information and communications technology is a key priority area. The Unit is an expert body that bases its work on multidisciplinary research and development expertise, and national and international cooperation.

The Unit is mainly engaged in the following tasks:

Tasks of the THL Information Structures and Classifications Unit:

Research, maintenance and development of information structures that support the operational processes of social care and healthcare;

<u>**Development**</u>, maintenance and dissemination of the structures, classifications and vocabularies necessary for client documentation through the national code server;

Research and Evaluation of structured client documents utilization and related changes in and impact on the social and healthcare systems, as well as in the health and welfare of citizens.

The Finnish <u>Society of Telemedicine and eHealth</u> was established in 1995 and aims to promote the health of the population through telecommunication and to disperse



the expert knowledge within healthcare. It has a close collaboration with other national and international organisations, healthcare service providers and users.

The activities of the FSTeH include:

- Development of professional expertise
- Arrangement of seminars, presentations, training courses, workshops, symposia
- Issuing of publications (both printed and electronic)
- Support of academic research
- Evaluation of current issues
- Collaboration with international organisations

The FinnSHIA, the Finnish <u>Social and Health Informatics Association</u>, is the national member society of the International Medical Informatics Association (IMIA) and the European Federation for Medical Informatics (EFMI). This means that the association poses a link between Finnish social and healthcare information technology, information management researchers and other stakeholders to international organisations. FinnSHIA has been established in 1974 and has – since then – expanded its activities in the healthcare industry and the social sector in general.

In general, research and development in health informatics is funded by the public sector, such as the Ministry of Social Affairs and Health, the Academy of Finland (the prime funding agency for basic research, operating within the administrative sector of the Ministry of Education) (, the Finnish Innovation Fund (SITRA - an independent public fund under the supervision of the Finnish Parliament) or from semi-public sector (such as the Finnish Funding Agency for Technology Development and Innovation - TEKES).

3.2.1 Patient summary and electronic health record (EHR)³⁶

In this study, the epSOS project's definition³⁷ of a patient summary was used as a general guideline. There a patient summary is defined as a minimum set of a patient's data which would provide a health professional with essential information needed in case of unexpected or unscheduled care (e.g. emergency, accident), but also in case of planned care (e.g. after a relocation, cross-organisational care path).

Lacking a standard definition, a patient's electronic health record (EHR) is here understood as an integrated or also interlinked (virtual) record of ALL his/her healthrelated data independent of when, where and by whom the data were recorded. In other words, it is an account of his diverse encounters with the health system as recorded in patient or medical records (EPR or EMR) maintained by various

³⁶ KanTa

³⁷ Global 360 2009



providers like GP, specialists, hospitals, laboratories, pharmacies etc. Such records may contain a patient summary as a subset. As of yet, fully-fledged EHR systems rarely exist, e.g. in regional health systems like Andalucia in Spain or Kronoberg in Sweden, or in HMOs (health maintenance organisations) like Kaiser Permanente in the USA.

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

Use of EHRs in connection to national eArchiving service

In 2002, the Finnish Government made the decision for "nationwide electronic patient records (to) be introduced by the end of 2007"38. The National Health Project Program was launched and an electronic patient record project was included in the program. Until that time, every service provider had its own patient record system and these systems usually were not interoperable. In 2004, the development of a core or minimum data set for use in all electronic health record systems begun. The Finnish minimum data set contains the following core data elements: information for patient identification, clinical data (such as diagnoses, investigations, procedures, medications, nursing data, physiological measurements etc), health risk data and other data, as e.g. a treatment will or an organ donor will. Until the fall of 2009, extensions to the core data set for specific clinical domains had been developed for: emergency care, occupational health, dental health, respiratory diseases, psychiatry, diabetes and vascular disease treatment and prevention, and maternity and child care.

In December 2006, the Parliament decided to introduce a national EHR archive (eArchive) in order to enable access and exchange of patient information across healthcare service provider organisations at the point of care, based on patient consent. KanTa, the National Archive of Health Information, will be composed of several national medical information systems: the ePrescription and national Pharmaceutical database, the eArchive (electronic archive of patient records) and online access for citizens to their personal prescription and medical record data.³⁹

For the use of EPRs, a national digital archiving service has been set up for health service providers, in which every organisation has their own patient record archive. However, the structure of the archives is uniform. All public service providers are obliged to have their patient record archive in the new system and private providers have to join the system if they have electronic archives. Every service provider will

³⁸ Decision-in-Principle by the Council of State on securing the future of health care, issued in April 2002

³⁹ Jylhä and Saranto 2008



have access to all archives through the national index service, controlled by patient consent. According to the original law, the system should be fully functional in 2011; however, the deadline is being postponed to 2014. From a technical perspective, all EHR systems joining the national eArchive are obliged to use a predefined structure. Finnish registries use international classification systems such as ICD-10 and ICPC-2 and the EHR minimum data set will also to a large extent be coded on the basis of these classification systems. The codes needed for the minimum data set (which essentially acts as a patient summary) are provided to EHR systems developers via the national code server. The accomplishment and implementation of the structured content of data, core data definitions, and national classifications and code services have prepared the ground for collaboration between patient data systems. Several regional services with most of the required functionalities are routinely operational. According to the future law, all public service providers will be obliged to provide data to the national eArchive by 2014, and the private providers by 2015 if they maintain electronic archives. The data, which is included in the Finnish national archive, will be expanded gradually. In the firs phase is the following:

Data stored in the Finnish national eArchive:

First phase

- Administrative/ demographics
- Electronic medication record
- GP record/ summary
- Medical record
- Referral and discharge letters
- Laboratory results
- Radiology reports
- Summary of nursing information
- Emergency care data
- Log information

Next steps

- Radiology, endoscopy etc images
- Medical statements
- Dental healthcare
- Biosignals

The Finnish eArchiving solution to EHR interoperability is not strictly speaking a Patient Summary solution. In its basic form, the records of each healthcare provider are archived and accessed separately. It is likely that a Patient Summary view, combining core data from the different EHRs, will be developed within the eArchiving



service, although such a view has not yet been specified. The current law only obliges to include "search information" such as the patient's unique identifier, healthcare service provider information and treatment period information in healthcare providers' records.

Although storage space for patient files, especially in hospitals⁴⁰, is seen as a challenge, the main challenge elated to EHR systems in Finland is the fragmented architecture of EHR systems. This affects both storage and proper retrieval and overview of medication information, as it can be stored in different parts of the EPR system. For instance, within an electronic patient record system, medication information may need to be entered separately in the physician's orders, the medication list, nursing care plans, nursing notes and patient information flow sheets - components which are currently not interoperable. All this means that healthcare professionals have to make several entries in order to fully document patients' medication information. In addition, changes in medication information have to be updated at every entry in order to make the new information available to all professionals with a legitimate concern in the matter. This merits consideration, as duplicated documentation and copy-paste methods used across non-interoperable systems expose patients to errors in medication care.⁴¹ With regard to the realization of the national level plans, the main challenge to be overcome in the near future is the upgrading of existing organisational and regional systems to the required national standards.

⁴⁰ European Patients Smart and Open Services (epSOS)

⁴¹ Korppas L and Rika 2010

eHealth

Figure 4: Patient summary in Finland





3.2.2 ePrescription⁴²

In the framework of this study and following work in epSOS⁴³, ePrescription is understood as the process of the electronic transfer of a prescription by a healthcare provider to a pharmacy for retrieval of the drug by the patient. In this strict sense, only few European countries can claim to have implemented a fully operational ePrescription service.

In 2002, a national ePrescription pilot was launched in Finland, which included the electronic transmission of prescriptions to collaborating pharmacies and decision support. The pilot was stopped because the system was not technically ready for implementation. However, all the experiences were reported and evaluated.

After that, the actual technical construction of the system took two years, and the first clinical pilot started in 2004. By the end of 2005, two out of four piloting healthcare units had implemented ePrescription in the electronic patient record. In spring 2005, the organisation of the national pilot was changed to a major consultancy company, which reorganised the administration entirely. The amount of produced ePrescriptions remained very small with about 1075 electronic prescription issued.

⁴² Valkeakari 2008

⁴³ European Patients Smart and Open Services (epSOS)



Between the stop and the relaunch of the pilots, legislation on ePrescriptions was accepted by the Parliament in December 2006 and placed in effect in 2007.⁴⁴ This will lead to a central ePrescription database, hosted by the Social Security Institution (KELA). The ePrescription database is meant to be fully integrated with the different existing ePrescription systems. As mentioned in section 3.2.1 on electronic patient records, the full implementation of electronic prescribing is connected to the realisation of the National Archive of Health Information (KanTa).

eHealth Strategies

During 2008, one of the main issues in the field of eHealth has been building the national ePrescription system. The central ePrescription database, hosted by the Social Security Institution (KELA), is functioning. ePrescription pilots started again in May 2010 in the first region.

Once ePrescription is fully operational, doctors can issue and sign ePrescriptions electronically as well as store them in the centralised system (Prescription Center). The Prescription Centre is a national database that stores the ePrescriptions and the dispensing entries made by pharmacies. During the first 30 months the ePrescriptions will have to remain readily available in the so called "active electronic prescription centre". After this period the prescriptions will be automatically transferred to a long term electronic archive, where they are stored for 10 more years and after which the data need to be destroyed. When all of the prescriptions made out to a patient are stored centrally in the Prescription Centre, doctors and nurses can, with patient consent, review the patient's medication regime in order to prevent adverse drug interactions and duplications. Patients may also request a pharmacist or assistant pharmacist to review their medication.

Reuse of medication information

After the implementation of the ePrescription system, all healthcare units and pharmacies will furthermore have access to a single Pharmaceutical Database. It contains information necessary for the prescribing and dispensing of pharmaceuticals, including their prices and compensability and any interchangeable products. The database also covers compensable emollients and clinical nutrients. Even after the implementation of the ePrescription system, patients will continue to have the right to choose to receive their prescription on paper.

Generally, the reuse of the collected medication data is possible, as prescription information can be used for supervision, drug safety operations, payment of drug reimbursements, and research for a period of up to 10 years following data removal from the Prescription Centre.

Remaining challenges have been identified with regard to the following issues; impact of the introduction of the new system on ways of working; negative attitudes among some of the healthcare professionals; the unavoidable overlapping time of

⁴⁴ The prescriptions are part of the EHR and thus electronic, but must be transmitted to the pharmacies by paper (and signature) – thus, they are not ePrescriptions in the sense of the epSOS definition.



the old and new system being simultaneously in use; unknown realization of the expected benefits⁴⁵.

National Operation 2004-2007 Connection to EHR archiving system Agenda Clinical pilot. ·Nation-wide use by National ePrescription pilot, including the ·Consultancy firm 2013. Reporting and evaluation of the stopped pilot. Pharmacy use by reorganises electronic transmission implementation end 2011 to the pharmacy and Technical construction of Legislation on decision support. Public Health Care a new system for ePrescription. ePrescription providers use by end 2012 Implementation Further ·Private Sector use by 2002 Implementation end 2013. 2002-2004 Toda

Figure 5: ePrescription progress in Finland

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3.2.3 eView and citizens' eHealth services

Complementing the eArchiving and ePrescription services, eView is a service for citizens wishing to view their own eHealth information This service is an integral part of the national eHealth services, and is already functional for the ePrescription data included in the ongoing pilot. The eView service is seen as a key tool for empowerment of citizens in the maintenance of their own health and in their participation in their care plan.

Citizens can view their personal information over the Internet. They can view their prescription information and patient records and print out a summary of their eprescriptions. 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 electronic ID.

E-prescriptions and dispensing data are available for view for a total of 30 months or 2.5 years from when the e-prescription was issued. Information stored in the electronic archive of patient records is available for as long as it remains in the archive (usually life long).

The eView service is one basis for an extensive program of citizen-oriented electronic health and social services, being developed as a part of a cross-sectoral

⁴⁵ European Commission 2008



governmental policy program for citizen's electronic services (SADe program, 2010 - 2014),

3.2.4 Standards⁴⁶

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

THL Unit for eHealth and eWelfare and SAINI as main providers In Finland, the THL Unit for Information Structures and Classifications is responsible for maintaining, producing and disseminating the most important classifications in social and healthcare. This provision of standards is connected to the development of national electronic health record systems, as it demands a consensus on open standards for interoperability.

Currently, the deployment of the eHealth structure is based upon nationally approved terms, classifications and codes, which are updated by the national code server. Furthermore, a nationally selected set of standards has been defined, based on international standards such as HL7, CDAR2, ISO/OID or DICOM. But still, critics say that common standards – both technical and especially semantic – are too few in Finland.

On a different area of standardization, the project SAINI, coordinated by SITRA and involving the Ministry of Social Affairs and Health, The Social Insurance Institution of Finland, the National Public Health Institute, the Association of Finnish Local and Regional Authorities, the Finnish Centre for Health Promotion and other partners proposed a roadmap for the implementation of online healthcare services for citizens.⁴⁷ The objective of the proposed architecture was to standardise technical solutions and services of present and future electronic services for citizens - particularly those that support citizens' health-related decision making, as well as the interaction and information flow between professionals.

3.2.5 Telemedicine⁴⁸

The use of telemedicine applications is recognised as beneficial to enable access to care from a distance and to reduce the number of GP visits or even inpatient admissions. Commission services define telemedicine as "the delivery of healthcare services through the use of Information and Communication Technologies (ICT) in a situation where the actors are not at the same location"49. In its recent

⁴⁶ Population Register Centre

⁴⁷ National Supervisory Authority for Welfare and Health

⁴⁸ Vuorenkoski, Mladovsky et al. 2008

⁴⁹ Finnish Government 1999



communication on telemedicine for the benefit of patients, healthcare systems and society, the Commission re-emphasises the value of this technology for health system efficiency and the improvement of healthcare delivery⁵⁰.

First experiments with telemedicine took place as early as 1969 and Finnish representatives have participated in telemedicine surveys and projects supported by the Nordic Council of Ministers and the Nordic University Network since the early 1990s. In 1999 for example, over 200 smaller telemedicine projects were registered, which were mostly conducted by hospitals.

Since then, a wide range of applications has been implemented and been running as a regular service in Finland, including the following:

Telemedicine applications in Finland:

- Teleconsultation (emergency transportation)
- Telediagnosis
- Telemonitoring
- Telelaboratory services
- Videoconferences (telepsychiatry, teleophtalmology)

Specifically, digital radiological image transmission is a standard procedure in major hospitals and teleradiology is also available in all university hospitals and in most central hospitals. Teleconsultation is not a common practice overall, but within certain specialties and patient groups (e.g. telestroke services) the services between hospitals are efficient.

Early experiences (1969) and further implementation of telemedicine

The service of consultations by televideoconferencing has increased since 2003. But in Finland, a direct televideoconferencing between the physician and the patient at their home is available only experimentally or in restricted pilot projects.

Overall telemedicine is regarded to be a positive solution to overcome geographical distances rather then a risk for patient safety. For future developments, the Finnish eHealth roadmap furthermore emphasises the importance of telemedicine in relation to the mobility of doctors. It is stated that "there will be companies renting out doctors, and some health centres will use these services when organizing their on-call duty rosters. The patient's right to choose a service provider will probably change in the future. In view of the jurisprudence of the European Court of Justice, this has already happened in certain cases involving the procurement of services from another Member State".

⁵⁰ Finnish Government 2000



3.3 Technical aspects of implementation

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

3.3.1 Unique identification of patients

The Finnish personal identity code or Finnish Unique Identifier (FINUID, or SATU in Finnish) 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 (SSIN, or HETU in Finnish), which functions as a unique identifier for Finnish citizens and permanent residents to eGovernment services. The personal identity code is needed in order to be able to apply for pensions and other benefits. It is also needed for the payment of wages, salaries and fees. The code is also essential in bank transactions, and the banks require it when one is opening an account.⁵¹ A personal identity code is also issued to foreigners who reside in Finland for over a year or permanently.

When providing citizens with a personal identity code, the Population Register Centre creates also an electronic identity for them (FINEID). The electronic client identifier is used for electronic user identification in secure online transactions. It is a dataset consisting of a series of numbers and a check character that helps identify Finnish citizens and, in accordance with the Municipality of Residence Act, foreign citizens permanently residing in Finland who are entered in the Population Information System.

The electronic client identifier is activated only when a person receives a certificate card, utilising the Population Register Centre's Citizen Certificate, for instance a chip ID card. The Citizen Certificate is an electronic identity, which contains, among other information, a citizen's first name, last name and an electronic client identifier.

3.3.2 Unique identification of healthcare professionals

In Finland, the National Supervisory Authority for Welfare and Health "Valvira" grants, upon application, the right to practice as a licensed or authorised professional and authorises the use of the occupational title of healthcare professional.

Under Finnish law, licensing is granted to the following professions:

⁵¹ Ruotsalainen, Doupi et al. 2007



Licensed professions in Finland:

Physician, dentist, pharmacist, psychologist, speech therapist, dietician, dispenser, nurse, mid-wife, public health nurse, physiotherapist, medical laboratory technologist, radiographer, dental hygienist, occupational therapist, optician and dental technician.

The protected occupational titles as defined in the Decree on Healthcare professionals are:

Occupational titles in Finland:

Orthopaedic technician, podiatrist, trained masseur, chiropractor, naprapath, osteopath, practical nurse for social and healthcare, psychotherapist, hospital physicist, hospital geneticist, hospital chemist, hospital microbiologist and hospital cell biologist.

Professionals entitled to use a protected occupational title are entered into the central register of healthcare professionals "TERHIKKI", maintained by the National Supervisory Authority for Welfare and Health.

The National Supervisory Authority for Welfare and Health can also grant an authorisation to practice to nationals of countries outside the EU/EEA and who have obtained their qualifications in a country outside of the EU/EEA.

3.3.3 The role of eCards⁵²

5.5.5

FINEID - Smart Citizen ID-card with PKI-based certificate

Persons registered in the population register are issued an identity card only if they apply for one and since 1999 (following studies undertaken from 1995 to 1997) the only available identity card has been the electronic FINEID card. FINEID is a smart Citizen ID-card with PKI-based citizen certificate. The data and certificates of the cards are provided by the Population Register, which acts as the issuing organisation; however FINEID cards are applied for and distributed by the local police.

Since the card is not mandatory and carries an out-of-pocket cost, very few people own one (by the end of June 2009, Citizen Certificates had been issued to a total of 259,000 people). Up to this point, only a small amount of services are available where the card can be used, but certain municipalities are already offering eHealth services based on patient identification by the Citizen Certificate (or alternatively, the eBanking identification, which is also based on the Population Register data and certificates). Instead passports are more common as travel documents and drivers licence are more common as identity documents.⁵³

⁵² Hämäläinen, Reponen et al. 2007

⁵³ IDABC, Country Profile Finland (update), 2009.



Health Insurance Card - KELA card

All permanent residents of Finland receive a personal health insurance card, the KELA card, which is distributed by the Finnish Social Insurance Institution "Kela"⁵⁴. This card is a plastic card with one-dimensional bar codes, which is sent automatically and at no cost to everyone covered under the Finnish social security system. By presenting the card at the pharmacy or at private clinics, citizens can get a direct reimbursement of the service costs (i.e. a discount equal to the amount covered by KELA). Until mid-October 2008, KELA used to also issue card with a photograph of the card holder which functions as identification in KELA offices, banks and post offices, as well as other organisations which choose to accept it as an official ID (not, however, outside Finland). Renewal of these cards is possible until 2014.

ID card with health insurance data

There is also the possibility of combining the national ID card issued by the police with health insurance data, and thusallow the ID card to function as a KELA card (with the exception of including the indication of pensioner status). The ID card is valid for five years and costs 40 euros. It can be used as a travel document in many European countries and as authentication token when logging into various government online services. If the person's health insurance details change while the ID card is still valid, a renewal is in order (again for the fee of $40 \in$).

European Health Insurance Card The European Health Insurance card is also issued by KELA and it is available to everyone covered under the Finnish health insurance system (since March 2010, also to Finnish pensioners residing abroad). About 400.000 EHIC plastic cards have been distributed.

Related to data storage, Finland has made a policy decision that no health related information is saved on the eCards. Cards are used only for identification either when receiving healthcare services in person or for online services.

For the purpose of identification of healthcare professionals, there is also the VALVIRA smart card and certificate, which validates competences in order to access KANTA⁵⁵ applications and health related information. It is also possible to electronically sign documents and other data transferred in the healthcare information systems.⁵⁶ The card is based upon the VALVIRA Central Register of Healthcare Professionals TERHIKKI (established in 2009), which offers an authentic database describing the capacity and competences of the medical professional. The responsibility for verifying healthcare professional electronic identities is being transferred fro VALVIRA to the Population Register Centre in 2010.

⁵⁴ Kela operates under the supervision of Parliament. The administration and operations of Kela are supervised by 12 trustees appointed by Parliament and 8 auditors chosen by the trustees. Kela has a 10-member Board of Directors that manages and develops its operations.

⁵⁵ KANTA is the national digital archive for health information, operated and maintained by the Social Insurance Institution (Kela).

⁵⁶ Hyppönen, Doupi et al. 2009



On a regional level, smart cards for a strong electronic identification of healthcare professionals are in use in 8/21 hospital districts and in 9% of the healthcare centres (2008 data). The rest of hospital districts and healthcare centres use a second password method with a password list or user names and passwords. In Finland, the former is available as a commercial solution of the banking sector and can also be applied in healthcare upon regional agreement within the healthcare system. The identifiers including user names and passwords had been fixed to the unambiguous identity number of an employee in 13 of the 21hospitals districts and 39% of the healthcare centres.

Challenging aspects regarding the development of eID and the deployment of eCards in are connected to the fact that there is a slow take-up of eCard technology due to slow spread of services facilitated by the same. Specifically with regard to healthcare, , the practical organisation of the smart card distribution to all healthcare professionals poses a logistic problem (organising the local registration and distribution facilities in the hospital districts), as well as financial burden, for local systems upgrade in order to be integrated into the national system.

Figure 6: eCards in Finland



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3.4 Legal and regulatory facilitators

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



phenomenon has to be addressed within the existing laws on professional liability, data protection etc.

As briefly mentioned in section 0, there are several important legal acts in Finland, which are connected to the deployment of a health information structure and eHealth applications. These are:

Legal acts related to eHealth:Personal Data Act from 199957Act on Experiments with Seamless Service Chains in Social Welfare and
Care Services from 2000Decree on the Storing of Patient Data from 200158Act on the Use of Electronic Social and Healthcare Client and Patient
Information from 2007, also called the Client Data ActLegislation on the Use of ePrescription from 2007

The objectives of the **Personal Data Act** are "to implement, in the processing of personal data, the protection of private life and the other basic rights which safeguard the right to privacy, as well as to promote the development of and compliance with good processing practice". This includes the collection, recording, organisation, use, transfer, disclosure, storage, manipulation, combination, protection, deletion and erasure of personal data. It is stated that a healthcare unit or a healthcare professional is allowed to process data "collected in the course of their operations and relating to the state of health, illness or handicap of the data subject or the treatment or other measures directed at the data subject, or other data which are indispensable in the treatment of the data subject". The Act sets conditions for the exchange of information (i.e. patient data) between different register controllers and for the storage of information in data files. Article 3 §13 stresses that sensitive data should be erased from the data file immediately when there is no longer a reason for its processing. The reason and need for processing shall furthermore be re-evaluated at five-year intervals at the longest.

The Act on Experiments with Seamless Service Chains in Social Welfare and Health Care Services and with a Social Security Card entered into force on 1.1.2000, with an original period of validity until the end of 2003. As of 1.1.2004, the Act was expanded to cover the whole country and its period of force was extended until the end of 2005. The Act was aiming to "to gain experience of arranging seamless service chains, and of ways of optimising the use of information technology so that it answers the needs of the clients of social welfare and healthcare services and general social protection, and of establishing how best to

⁵⁷ Act on Personal Data of 22 April 1999/523;

⁵⁸ Decree on the Storing of Patient Data 2001/99



allocate information technology resources in these activities in a sensible way". In relation to reference health data, it defines that this data can be disclosed when: 1) there is a written consent of the client 2) for the purposes of scientific research and statistics according to the Act on the Openness of Government Activities or other legislation and 3) in situations such as the issuing of new cards by the insurance company, where the consent of the client cannot be obtained. The main focus of the legislation was to support the development of regional cooperation for seamless services, promote continuity of care and advance the building of regional information service systems and adapters between existing legacy systems.

The Decree on the Storing of Patient Data of 2001 regulates the management of medical records and related documents such as referrals, laboratory results and radiology documents. The Decree regulates in a detailed way the design and implementation of patient data storing systems, the right of access to the documents, the right to make entries in the documents, the minimum level of information to be registered about the patient, illness and treatment time entries etc.

The Client Data Act from 2007, covers archive services, encryption and certification services as well as the patient's access to data. The Client Data Act provides the patient with a right to a medical record, carefully updated and safely stored by the health professional. Medical records need to be kept in electronic format. By 2011 the law requires all public healthcare units as well as private healthcare units that do not use paper-based archives, to be incorporated into the electronic archiving system. Article 11 of the Act specifies that a medical record should consist of at least a so called General Medical Record (GMR) and a patient consent record. One GMR should be kept for every patient by the general practitioner in charge of the patient's treatment. The Act also states that the national eArchiving service for electronic patient records will be maintained by the Social Insurance Institution (Kela)⁵⁹, using a unique number per patient. The archive will be accessible to all physicians who are involved in the provision of care to the patient, after obtaining consent. Individuals have access to their own patient records, are entitled to see the access log of their care record and to obtain a copy.

According to the **Act on the Use of Electronic Prescription** and the Decree of the Ministry of Social Affairs and Health (which entered into force on 1.1.2008), electronic prescriptions are allowed for medicines for human use. The law further states that the central national electronic prescription database will be maintained by KELA, the Social Insurance Institute of Finland. In this system prescriptions will be sent directly in electronic form from the physician's office to the central database to which pharmacies have electronic access. All service providers are obliged to make prescriptions electronically by 2011. Patients' consent is not required for writing an electronic prescription, but the patient will still have the possibility to deny the use of

⁵⁹ Article 14



an electronic prescription and receive his prescription on paper. When the prescription is made electronically, the patient does have to be informed about the national data base service so that he is aware of the data exchange and archiving operations that will take place. The fact that the patient is provided with this information has to be noted in the patient's record in order to free the healthcare provider from the obligation to obtain consent.

3.5 Financing and reimbursement issues

In Finland, funding for health technology systems is mainly provided by public and private sources. Private funding for ICT support has been secured since 1998 through research and development programmes of the Finnish Funding Agency for Technology Development and Innovation(TEKES⁶⁰). TEKES provides funding for companies and consortia, for example through the "FinnWell programme", and also direct corporate funding. Healthcare organisations spend about 2% to 3% of their operating budget on IT.

The Ministry of Social Affairs and Health has financed and continues to finance work on national specifications through separate budget funding (e.g. Association of Finnish Local and Regional Authorities, THL, KELA, HL7 Association). The Ministry of Social Affairs and Health has provided EUR 11 million cluster projects between 2006 and 2009 (50% funding contribution). ESF funding has also been used in development projects. The central government has contributed a total of EUR 33 million to the construction and introduction of national services (archive, prescription centre, eView for citizens) between 2006 and 2010, and plans to be contributing 55 million EUR between 2011 and 2014 for development, implementation and operation of the system. Thereafter, services will be funded through user fees collected from healthcare providers.

In sum it can be stated that, although ambitious, Finland's eHealth plan is being delivered on a fairly modest budget.

Generally, the financing for healthcare IT projects has been provided through several channels. Thereby, the coordination of financing and the lack of permanent budget funding have proved to be challenging. Also, financial management has been shown to be insufficiently effective in ensuring uniform implementation.

3.6 Evaluation results/plans/activities

From a public policy perspective, evaluation is a key activity in the policy-cycle. It provides insights into the success or failure of a policy or project and leads to new policy goals and new methods of implementation. The need for evaluation of eHealth

⁶⁰ Every year, Tekes grants around EUR 600 million towards innovative projects aimed at generating new know-how and new kinds of products, processes, and service or business concepts. Funding is also available for developing work organisations.


policies and projects has been stressed time and again by the EC, not least in order to further the spread of eHealth in the process of healthcare delivery.

Finnish "Check Point Reports" from 2003, 2007 and 2008 evaluate eHealth

Evaluation activities in Finland are mainly carried out by THL or the Ministry of Social Affairs and Health. Past evaluations of the progress made in nation-wide eHealth deployment have been published under the so-called "Check Point Reports", so far published in 2003, 2007⁶¹ and 2008. Also evaluations focusing on specific topics, such as e.g. the first ePrescription pilot have also been undertaken (see section 3.2.2, when the ePrescription pilot was stopped and an assessment was carried out in order to understand remaining technical and organisational obstacles.

During the period 2003-2007, regional pilots of EHR core data development and implementation funded by the Ministry were also subjected yearly to evaluation by the Ministry of Social Affairs and Health (internal reporting).

With regard to the national eHealth implementation plans, it is still too early to evaluate the changes in care processes and the possible impact on healthcare quality, safety and effectiveness. However, the need to follow up the change and its effects on citizens and professionals has been identified by the Ministry of Social Affairs and Health. The planning of a large scale evaluation of the national eHealth developments has been started. In the fall of 2008, the Ministry commissioned the National Institute for Health and Welfare (THL) over a 6 month period to draw up an evaluation framework for the national eHealth services. The project was finalised and delivered its final report in April 2009 (Stakes 2008c).

The evaluation plan framework was created as a joint effort of all interested research and development parties in Finland. The Finnish Ministry of Social Affairs and Health will still need to collaborate with funding bodies to create a platform for starting the actual evaluation work.

4 Outlook

Finland has been working on the development and deployment of IT in healthcare since the beginning of the 1990s and has since continuously raised questions of centralised systems and interoperable archives for data storage and access. These commencements were combined into an overarching project of electronic patient records, which includes different types of eHealth applications and system development. Hereby, the technical framework builds upon local health IT, which has been deployed by municipalities at an early stage.

⁶¹ National Institute for Health and Welfare (THL) 2010



This development – especially the early political commitment and the drawing upon existing systems – made Finland a well-prepared country for any eHealth commitment. In recent years, it became apparent that the main obstacles Finland will face or is facing are interoperability issues of the different local systems and the high level of management and decision-making decentralisation, as this leads to overlapping IT investments and a lack of uniform terminology.

At present implementation is underway. The eArchiving system for citizen data – including health and medication information – is the crucial data node, which is directly linked to the EPR project. The Finnish Government is aiming to make the use of the system compulsory and declare full implementation by 2015.

In sum, it can be stated that the full deployment of the national EPR system will significantly change Finnish eHealth and it remains to be seen how aspects of decentralisation and interoperability will hinder full deployment and smooth working of the system in general.



5 List of abbreviations

DRG	Diagnosis Related Group				
EC	European Commission				
EEA	European Economic Area				
EFMIA	European Federation for Medical Informatics				
EHR	Electronic Health Record				
EMR	Electronic Medical Record				
EPR	Electronic Patient Record				
epSOS	European patients Smart Open Services				
ERA	European Research Area				
EU	European Union				
FINEID	Electronic Identity in Finland				
FinnSHIA	Finnish Social and Health Association				
FINUID/SATU	Finnish Unique Identifier				
FSTeH	Finnish Society for Telemedicine and eHealth				
GDP	Gross Domestic Product				
GP	General Practitioner				
HCP	Healthcare Provider				
HL7	Health Level Seven International (authority on standards for interoperability)				
HMO	Health Maintenance Organisation				
HPC	Health Professional Card				
HTA	Health Technology Assessment				
ICT	Information and Communication Technology				
ID	Identification (e.g. number, card or code)				
IHTSDO	International Health Terminology Standards Development Organisation				
IMIA	International Medical Informatics Association				
IT	Information Technology				
KanTa	Finnish National Archive of Health Information				



KELA	Social Insurance Institution of Finland					
LSP	Large Scale Pilot					
MSAH/STM	Ministry of Social Affairs and Health					
NHI	National Health Insurance Scheme					
OECD	Organisation for Economic Co-operation and Development					
PARAS	Restructuring Municipal Services Project					
PHS	Personal Health System					
R&D	Research and Development					
SSIN/HETU	Social Security Identity Number					
SNOMED	Systematized Nomenclature of Medicine-Clinical Terms					
TEKES	Finnish Agency for Technology and Innovation					
TERHIKKI	Central Register of Healthcare Professionals					
THL	National Institute for Health and Welfare					
VALVIRA	National Supervisory Authority for Welfare and Health					
WHO	World Health Organization					



6 Annex

6.1.1 Annex 1: Compound indicators of eHealth use by GPs

Compound indicator name	Component indicators	Computation
Overall eHealth use	 Electronic storage of individual medical patient data Electronic storage of individual administrative patient data Use of a computer during consultation with the patient Use of a Decision Support System (DSS) Transfer of lab results from the laboratory Transfer of administrative patient data to reimbursers or other care providers Transfer of medical patient data to other care providers or professionals ePrescribing (transfer of prescription to pharmacy) 	Average of component indicators
Electronic storage of individual medical patient data	 A2a - Symptoms or the reasons for encounter A2c - Medical history A2c - Basic medical parameters such as allergies A2d - Vital signs measurement A2e - Diagnoses A2f - Medications A2g - Laboratory results A2h - Ordered examinations and results A2i - Radiological images A2j - Treatment outcomes 	Average of component indicators
Electronic storage of individual administrative patient data	- A1 - electronic storage of individual administrative patient	A1 value
Use of a computer during consultation with the patient	- B2 - Computer use during consultation	B2 value
Use of a Decision Support System (DSS)	 B3a - Availability of DSS for diagnosis B3b - Availability of DSS for prescribing 	Average of component indicators
Transfer of lab results from the laboratory	 D1e - Using electronic networks to transfer prescriptions electronically to dispensing pharmacists? 	D1e value
Transfer of administrative patient data to reimbursers or other care providers	 D1a - Using electronic networks to exchange of administrative data with other healthcare providers D1b - Using electronic networks to exchange of administrative data with reimbursing organisations 	Average of component indicators
Transfer of medical patient data to other care providers or professionals	 D1c - Using electronic networks to exchange medical data with other health care providers and professionals 	D1c value
ePrescribing (transfer of prescription to pharmacy)	 D1d - Using electronic networks to transfer prescriptions electronically to dispensing pharmacist 	D1d value

Dobrev, Haesner et al. 2008



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Reports and Memorandums of the Ministry of Social Affairs and Health 2013:11

Workshop Report

Peer Review

eHEALTH STRATEGY AND ACTION PLAN OF FINLAND IN A EUROPEAN CONTEXT

Helsinki, Finland 26–27 February 2013







This expert peer review has been facilitated by EHTELconnect membership services



Peer Review eHealth Strategy and Action Plan of Finland in a European Context

Reports and Memorandums of the Ministry of Social Affairs and Health 2013:11

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Peer review eHealth Strategy and Action Plan of Finland in a European Context

Foreword

Finland has been eHealth forerunner with a long history of digitalized health care information. We are now implementing national eHealth solutions which will make standard format patient and medication information available for patients and health care professionals.

EU and OECD have been doing surveys on eHealth development and policy within EU countries, Finland has regularly been one of the top countries. Next survey will be published within few months. At this phase of national development minister of Health and Social Services Maria Guzenina-Richardson wanted to get a more focused expert view based on wider material and deeper understanding that is possible with these more general questionnaires. This review will be used also with eHealth strategy process.

I would like to thank THL for arranging this review process and EHTEL experts for their valuable comments and the time they devoted to this work.

Päivi Sillanaukee Permanent Secretary Ministry of Social Affairs and Health

On behalf of THL we wish to thank EHTEL for its valuable contribution and for placing its network of such diverse expertise in eHealth at the disposal of the Finnish eHealth system. The input of the recognized international EHTEL experts in this very constructive panel was priceless. We also wish to express our gratitude to the Ministry of Social Affairs and Health Finland for making this review possible. We are grateful to the experts from the Health Insurance Institution Finland (Kela) for their contribution to the workshop.

The results of the review will not only be exploited in governmental policy outlining on the strategic level of eHealth and eWelfare in Finland but also in the refinement of the new role of THL, in which it has assumed operational leadership in the deployment of eHealth services. Furthermore, these messages from the international eHealth community conveyed to us by the reviewers shall be dealt with also among professionals at all levels of the Finnish health and social welfare system.

Päivi Hämäläinen, Director of Department Information Department THL – National Institute for Health and Welfare

Vesa Jormanainen, Chief of Unit Information Department THL – National Institute for Health and Welfare



Background and Peer Review Mandate:

The Ministry of Social Affairs and Health of Finland initiated an expert peer review of the eHealth Strategy and Action Plan of Finland and its positioning in international policy discussions at European level. This meeting report aims at providing useful content for the public authorities of Finland in their elaboration of various national strategies and plans.

This review is facilitated by EHTEL in the context of the EHTELconnect service package that the Association offers to its Members. EHTELconnect is intended to enable access to information, experience and expertise across the eHealth domain for EHTEL members.

European eHealth Experts	(in alphabetic order):
Tom Christensen	Deputy Director, Helsedir, Norway
Georg Heidenreich	Standardisation expert, Siemens, Germany
Jacob Hofdijk	Director, Casemix, Netherlands
Ehud Kokia	Immediate past Director-General of the Hadassah Medical Organization, Israel
Mats Larson	Owner, Bilthong AB, Sweden
Luc Nicolas	Senior Projects Manager, Federal Public Service Public Health, Belgium
Jan-Eric Slot	CEO, IHTSDO, Denmark
Jacqueline Surugue	President of FIP, Centre Hospitalier Georges Renon, France
Eddie Turnbull	Director for eHealth, NHS, Scotland, United Kingdom
Moderator	
Madis Tiik	CEO, Hekardi Ldt, Estonia
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Stephan Schug	EHTEL Chief Medical Officer (Rapporteur)
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Jari Porrasmaa	Consulting Officer (MoSH)
Jari Suhonen	Project Manager (THL)

Participants at the Peer Review Workshop

EXECUTIVE SUMMARY

In early 2013, the Ministry of Social Affairs and Health of Finland requested an expert peer review of the Finnish eHealth Strategy and Action Plan. It was organised by the European Health Telematics Association (EHTEL¹) in the context of the EHTELconnect² service package. The meeting took place in Helsinki, Finland, on 26/27 February 2013. Finnish plans and achievements were introduced by 15 Finnish presenters from the Ministry, the National Institute for Health and Welfare (THL) and the Social Insurance Institution of Finland (KELA). The peers – invited and coordinated by EHTEL – were ten senior experts from a range of European, and nearby, countries, including three members of the EHTEL team.

This report summarises the proceedings of the peer review meeting and its conclusions. The document is structured as follows: This executive summary lays out the key messages and is supported by summaries of all parts of the report. The full report starts with a small section ("i") on its scope - also providing a significant disclaimer - and continues with an introduction (Chapter 1) outlining the aims of the peer review meeting and its methodological approach. Chapter 2 describes the organisation and financing of Finland's healthcare system. Chapter 3 examines the Finnish health and social care system's policies and governance and relevant legal and regulatory frameworks. Chapter 4 describes the eHealth architecture and its application to social care. Chapter 5 examines patient eServices, also in relation to a wider eGovernment perspective. Chapter 6 offers some insights into health professional views on eHealth, particularly in the domain of ePrescribing. Chapters 7 and 8 assess the foundation of interoperability, i.e., use of standards, structured data, and coding services. Chapter 9 highlights registers and secondary data use. The report's conclusions are given in Chapter 10 using the structure of a strengths, weaknesses, opportunities, and threats (SWOT) analysis. This analysis distils the expert peer reviewers' lessons learned at the review, and highlights the main opportunities for progressing Finland's health and social care domains through a well-conceived eHealth deployment.

Aim

The Ministry of Social Affairs and Health of Finland initiated this two-day expert peer review of the eHealth Strategy and Action Plan of Finland in order to better understand its positioning vis-à-vis international policy discussions at European level. The workshop's aim was to assist the Finnish authorities in streamlining their strategy, legislation and deployment of the Finnish eHealth Infrastructure and Services (KanTa), including the National Archive of Health Information (eArchive).

The workshop covered eight aspects of Finland's health and social care. These eight domains of activity were presented systematically to the visiting peer review group. The subjects covered ranged from a general overview (to permit a clear understanding of the Finnish system and approach), to more organisational and user-related perspectives, and more technical issues such as standards, structured documentation and secondary data. The presentations were on: the healthcare system of Finland, its organisation and financing; policies, governance and legislation; Finnish national eHealth architecture and its extension to social care; patient and citizen eServices in health and social care; a user organisation perspective; the use of stan-

¹ EHTEL, the European Health Telematics Association is a multi-stakeholder organisation, based in Brussels, Belgium. Its members include European health and social care authorities (cf. <u>http://www.ehtel.eu</u>).
² The association has a corvice for its members. It is DUMENT.

² The association has a service for its members called EHTELconnect: it involves peer reviews of the eHealth services offered around Europe (cf. <u>http://www.ehtelconnect.eu</u>).

dards; structured documentation and terminology work; and secondary data. After each presentation, the peer reviewers had the opportunity to comment critically on the presentations. A summary of the presentations follows.

The healthcare system of Finland: its organisation and financing

The 2011 report on *Socially Sustainable Finland 2020* formed the basis for this presentation. It included details on the country's financing model of its primary care and secondary care health domains. Finland has a system of universal benefits and financing. Like the other Nordic countries, the health system is based on a common taxation system. Demographic changes are affecting both the people of Finland as well as the country's health personnel. This ageing challenge affects Finnish income security, social and health care services, and the prevention of various health problems and risks.

Comments from the peer reviewers related to Finland's commitment to equality of access to health and care, the country's use of data on diagnosis groups, and the future potential of adding a number of performance measures.

Policies, governance and legislation

There are many overlapping policies in Finland; hence, the challenge of implementing eHealth is a considerable one. A number of questions are currently being posed by the Ministry of Social Affairs and Health of Finland around the potential use of open data, information exchange, third party use, knowledge management, and usability. In historical terms, Finland has moved from a series of information systems "islands" to a more systematised approach. While the system caters for flexibility at a local level, it creates a highly structured and centralised information repository – that includes lifelong electronic health records for all Finnish patients.

Comments from the peer reviewers related in a positive manner to the incrementalism and flexibility of the Finnish system. Of importance is the need to examine the "big picture", the strategic benefits, the underpinning policies, and the ultimate purposes of eHealth in Finland. The precise motivations and incentives of the three main health stakeholders – decision-makers, healthcare professionals and management, and patients – for using health data will need to be borne carefully in mind. Interest was shown in the degree of centralisation of the approach selected by Finland, and details of the system's components.

Finnish national eHealth architecture and its extension to social care

Planning and analysis for Finland's eHealth architecture started in 2010, and involved an examination of past progress. This investigation was viewed as important for planning purposes. Today, the country's use of various information technology (IT) applications is generally higher than the European mean in both primary health care settings and in secondary care. Finnish health professionals have to use many different systems and interfaces in their workplace. For example, a total of seven different electronic health record systems are used. The main focus for future work between 2011-2016 is eAccess for citizens, an eArchive, ePrescribing, and the patient care summary. Provisional systems have been implemented on certain installation sites.

Comments from the peer reviewers related particularly to the governance, financing, and organisation of the eHealth architecture system. More precise questions concentrated on the change management system, legacy systems, certification, work organisation and ergonomics, and access and retrieval.

Patient and citizen eServices in health and social care

Plans and strategies for using IT for social welfare and health care have existed in Finland for nearly 20 years. Details were offered about the ways in which patient access services in KanTa are organised, and about the SADe programme, where the long-term vision is to help citizens to take responsibility for their own well-being and prevent various health problems.

Questions posed by the peer reviewers related to the notions of patient consent, access management (opt-in/opt-out), the usage of health data by healthcare providers, and the use of smart cards for health professionals.

User organisation perspective

The inclusion of professional users' perspectives and requirements was described using the setting of the Finnish ePrescribing service. The focus was on the public and private sectors from the perspective of two sets of stakeholders, physicians and IT management. ePrescribing use differs in the various areas of Finland. The system has developed substantially over the past three years, between 2010-2013. In March 2013, on average, in Finland 66% of hospital districts are using ePrescribing. In the country, this systematic approach to the introduction of ePrescribing is very much appreciated. A number of risks have, however, been perceived. They relate to specifications, timetabling, usability, and acceptance of structured documentation. Finland is working to manage and mitigate these challenges.

Questions and observations made by the peer reviewers fell into several categories: the relationship of the Finnish situation with the international context; the business side of implementation and incentives/motivation; the technology solutions sought; and the opinions of physicians, pharmacists, and patients.

The use of standards

The Finnish standardisation process was covered from the perspective of the solutions chosen or implemented and their relationship with international interoperability standards. Several aspects were introduced. They included Finland's national code server (established from 2002 onwards); Finland's role in the European epSOS large-scale pilot; and the goal of establishing a cross-border ePrescription pilot with Sweden.

Peer reviewers noted that Finland adopts international standards effectively, and is involved in meaningful international activities. Finnish extensions to standards do not block interoperability. Within its work in epSOS, Finland is moving towards the use of Integrating the Healthcare Enterprise (IHE) profiles. Particularly with regard to Finland's eArchive, it was felt that in allowing the tracking of events and record contents through to outcomes, it could act as a rich source of analysis – in effect, revealing a patient's journey through various points of contact and service.

Structured documentation and terminology work

Finland has a long tradition in defining life-long, structured health records. This work was covered from the point of view of THL, the relevant national organisation. Finnish structured documentation and the terminology work chosen or implemented were presented. The ways in which the patient summary and the national archive will be handled from 2014-2016 were also introduced. Finland has a roadmap that defines the documentation and terminology work that is needed by 2016. Using and adapting the relevant international standards, Finland has defined a clear-cut structure for the patient summaries to be copied to the eArchive life-long electronic health record.

The peer reviewers understood the patient summary as the ideal basis for integrated care. They proposed the updating of the name of the eArchive e.g., to "Living Archive" or a name that is closer to the notion of an active, life-long electronic health record.

Registers and Secondary data

THL is the national organisation that is also responsible for health statistics, e.g., on social and health services, alcohol and drugs, social protection and health expenditure. It organises the registration of health data, analyses it, publishes the data, and interacts with the various responsible international organisations such as the World Health Organisation. Finland has many different health registers, the oldest one being for cancer. In the context of the expert review, two registers deserved special attention: the HILMO hospital discharge register, and the AvoHILMO register of primary care visits. Both could provide essential data and insight into the healthcare changes induced by the roll-out of the eKanta/eKansa approaches.

The peer reviewers offered many observations related to the registers and their data quality; the targeting of health care provision for those who are really in need of it; pseudonymisation; patient safety and attention to medication errors; benefits and outcomes of the data; and measurement, and performance and quality indicators.

SWOT analysis

The list of observations from the different peer reviewers attending the meeting has been categorised according to a SWOT (strengths, weakness, opportunities and threats) analysis framework. Proportionally speaking, far more strengths and opportunities were perceived than weaknesses and threats.

Strengths

Finland is at a world-level benchmark in terms of eHealth.

- There is a strategic change programme occurring in Finland that provides a compelling vision of integrated healthcare.
- Finland's way of bringing health and social care together provides an excellent setting for other countries to start thinking about re-design of the social and health care systems.
- Two Finnish sub-systems are particularly impressive: they are the ePrescribing initiative and the registries/secondary data collections.
- Three aspects of the Finnish process are noteworthy: these are the early start made by Finland; the general overcoming of resistance to change; and the system's timeliness and responsiveness.
- Finland has successfuly established a wide diversity of fit-for-purpose components in terms of its eHealth support for its health and social system."

Weaknesses

- The experts had expected to hear more about how Finland justifies its investment and expenditure on eHealth, and explanation of how the country measures the benefits of its system and ensures maximum adoption by clinicians and citizens.
- There appears to be insufficient focus in Finland on the context of care itself, and on the services such as new care pathways, chronic disease management, and patient empowerment which will contribute to the necessary modernisation of the health care system.
- Of particular concern is how to get healthcare practitioners to act as coaches and guides to support health care improvement ("clinical champions"), working with "communities of patients" or "communities of providers".
- Focus is needed e.g., on what the health system overall is attempting to achieve, and on what the crucial policy and political decisions are that underpin any of the choices of ITbased health systems and technologies.

Opportunities

Policy, governance, and organisation

Find the disruptive innovation element of the health process; Focus on the creativity of the actors involved, and the incentives that the actors require to act; Build on the various components of the system. All the various components in the system(s) mean that Finland is "sitting on a gold mine!"

Leadership, business and benefits

Consider Finland's leadership position with regard to the transformation of health and care systems; Document the clinical effects of changes to the system; Measure the quality of health outcomes; Adapt quantitative indicators.

Opportunities for EHTEL and/or for Finland and EHTEL working together Finland could showcase more widely its eHealth solutions to other countries in Europe. Together or in parallel – EHTEL could help to build and expand the peer review scheme and model; Showcase the Finnish solutions; Compare and contrast Finland's approach to those of other countries.

Threats

- Aspects of data overload, privacy and security were identified by the peer reviewers as important, as too was eldentity. The main messages with regard to areas to which the Finnish authorities need to pay particular attention were as follows:
- Pay even more attention to timeliness and responsiveness; Pay attention to the risk of data overload; Be aware of possible threats to the information system; Consider alternative approaches for identification, health data, legacy systems and interoperability; Consider various technological and organisational design issues, e.g., generic eID, and the roles of public authorities and private vendors.

Conclusions

Finland has been involved in long-term development of its eHealth systems and services, developing from a mainly localised approach towards a more national-level approach that maximises the benefits of local ownership and flexibility. It is operated within an over-arching structure of information sharing and standardisation. There has also been an impressive degree of regionalism and local democracy. Finland has managed to track its eHealth work systematically over time. Hence, its authorities are able to see clearly the trends that have developed over a 30-year period. The basic openness, trust, and transparency apparent in Finland makes it a very helpful setting in which to develop eHealth systems.

Finland introduced digital documentation quite early. Health care quickly became paperless. Since Finland's "first generation" tools have now reached their limits, the country has to move to a next generation of services. Finland is therefore now in a good position to become an early adopter of innovative and further new concepts and methodologies.

Of clear strategic opportunity are the country's health and social care policy, governance, and organisation, its leadership, and the potential business and health/care benefits. It could certainly showcase more widely its eHealth solutions to other countries!

SCOPE AND DISCLAIMER

This brief overview outlines the scope of this report. It also identifies some reservations with regard to the report content (disclaimer).

Scope of this report: This report is intended to be a public document that may be published by either the Ministry of Social Affairs and Health of Finland or by the National Institute for Health and Welfare (THL). The report's aim is to assist the Finnish authorities in streamlining their strategy, legislation and deployment of the Finnish eHealth Infrastructure and Services (KanTa), including the National Archive of Health Information (eArchive). With this aim in mind, the report provides a high-level description of the Finnish health and care plans and the current implementation of the system, accompanied by targeted feedback from an international group of eHealth experts.

A brief overview of the main elements of the Finnish health and social care systems, and the supporting eHealth, presented by the Finnish authorities is summarised in each section of this report. Following this the feedback, comments, observations, and comparisons made by the experts present are captured. A series of observations, gathered from comments made by the visiting European eHealth experts and the members of the EHTEL team, is presented at the end of the report. Several additional individual interviews are provided in annex.

Disclaimer: The EHTELconnect expert peer review is called a "review" rather than an "evaluation" or "benchmarking".

This 26/27 February 2013 expert peer review exercise in Finland was not intended to undertake either a scientific evaluation based on a robust and well-established methodology or to benchmark Finland specifically against other countries. Where possible, however, attempts have been made to compare and contrast the Finnish experiences with those of other European countries and their neighbours. This is represented by examples or anecdotes described by the European eHealth experts who were present at the review.

Finland is currently in a process of reorganisation of health and social care: One option under debate in the government planning is to reduce the number of the municipalities involved while maintaining the responsibilities. 1

PURPOSE AND OBJECTIVES OF THE MEETING AND STRUCTURE OF THE DOCUMENT

The Ministry of Social Affairs and Health of Finland requested an expert peer review of the eHealth strategy and Action Plan of Finland, organised by the European Health Telematics Association (EHTEL) in the context of the EHTELconnect service package. This took place against the background of the January 2011 launch of Finland's *Socially sustainable Finland 2020. Strategy for social and health policy.*³ The meeting took place in Helsinki, Finland, on 26/27 February 2013.

Short descriptions of each of the presentations made by personnel from the Ministry of Social Affairs and Health of Finland and the National Institute for Health and Welfare (THL) are given in this report, so as to facilitate an understanding of the Finnish health and care system on the part of readers who were not present at the expert peer review meeting.

The expert peer review constitutes a kind of "second opinion". The exercise provides a diverse range of feedback from eHealth experts who work in a variety of fields throughout the European Union. The bodies represented by experts included public health authorities, technology companies, standardisation and similar bodies, and hospitals.

Overall, the experts expressed their appreciation of the comprehensiveness and the quality of the material provided to them as visitors. The outcome of the review meeting is this meeting report.

The document is structured in the following way: this introduction outlines the aims of the peer review meeting and its methodological approach. Chapter 2 describes the organisation and financing of Finland's healthcare system. Chapter 3 examines the Finnish health and social care system's policies and governance and relevant legal and regulatory frameworks. Chapter 4 describes the eHealth architecture and its application to social care. Chapter 5 examines patient eServices, also in relation to a wider eGovernment perspective. Chapter 6 offers some insights into health professional views on eHealth, particularly in the domain of ePrescribing. Chapters 7 and 8 assess the foundation of interoperability, i.e., use of standards, structured data, and coding services. Chapter 9 highlights registers and secondary data use.

The report's conclusions are given in Chapter 10 using the structure of a strengths, weaknesses, opportunities, and threats (SWOT) analysis. This analysis distils the expert peer reviewers' lessons learned at the review, and highlights the main opportunities for progressing Finland's health and social care domains through a well-conceived eHealth deployment.

³ <u>http://www.stm.fi/c/document_library/get_file?folderId=2765155&name=DLFE-15321.pdf</u> The report was published in English on 25 February 2013. Accessed 27 March 2013

2

THE HEALTHCARE SYSTEM OF FINLAND: ITS ORGANISATION AND FINANCING

Socially Sustainable Finland 2020 is a strategy document published by Finland in January 2011. This clear and informative introductory presentation was based substantially on the documentation provided by this policy document.

2.1 INTRODUCTION BY THE FINNISH DELEGATION

Hannu Hämäläinen, Ministerial Adviser, Ministry of Social Affairs and Health of Finland

cf. doc Fin Peer Review Day 1-1 Hannu Hämäläinen MoSH Healthcare System Introduction.pdf

Finland has a system of **universal benefits and financing**. As Mr Hämäläinen said, "Finland's constitution states that everyone [in the country] has the right to enough social and health care services when they need it." However, today the current economic situation perhaps poses difficulties to providing that universalism.

In Finland – like the other Nordic countries – the health system is based on a **common taxation system**. Five years ago, in 2008, the average EU27 expenditure on social protection was 26-27 % of the gross domestic product (GDP). Finland was spending exactly that amount. However, it now spends somewhat less than the mean amount on health and social protection as determined by the Organisation of Economic Co-operation and Development (OECD).

2.1.1 Demographic challenges affecting health personnel and the people of Finland

All the European Member States are now experiencing **similar challenges** to Finland. In this sense, "[Finland] is in no way different from the other Member States".

One of the subjects pursued jointly by the 27 members of the European Union is **active and healthy ageing**. Finland too is in a period of rapid large-scale demographic change. In the 1940s and 1950s, there was a heavy post-Second World War baby boom which has now resulted in a very fast ageing process. By 2050, Finland will have added 10% to its social expenditure, "but this is something which not everyone wishes to see happen."

In Finland, as Mr Hämäläinen announced, "Surveys show that people are living well and have a good functioning capacity". At the same time, overall, "the [Finnish] are satisfied, and people think the health and social services are good." ... "About 80-85% of those who responded to a 2007 survey, think that [the health system] is good", and Finland's hospital services are good. The most substantial difficulties are encountered by Finnish people mainly in the last two or three years of their lives. This "compression of disease" has been achieved as a result of better health maintenance.

In Finland, there are three basic elements to this ageing challenge: **income security**, **social and health care services**, and the **prevention of various health problems and risks**.

2.1.2 Financing and Finnish municipalities

At the **municipal level**, there are more and more people who are working in specialised health care, and fewer people are employed in primary care or in elderly care. During the last 5-10 years, specialist health care has received substantially more resources, while primary care has not been subject to the same attention. The average age of people working in health and social care in Finland has been maturing – in 2009, the average of personnel was around 45 years old. Many employees will be retiring shortly. Since Finland has a diminishing amount of manpower, it needs to introduce more effective ways of providing health and care services. The carefully managed introduction of **information and communication technology (ICT) tools and services** will act as a key enabler for this more effective provision of services.

On **financing** in somewhat more detail: "Finland has one of the most decentralised social and health care systems in the whole world. The local authorities are autonomous." Public services are funded mainly by tax revenues collected by the state and municipalities.

Currently, 201 authorities are responsible for organising primary health care and specialised medical care in 320 **municipalities**. Each municipality has on average around 6,000 inhabitants (ranging from less than 1,000 to 600,000) whereas, in many other European countries, the average population of an equivalent administrative area is about 200,000 people.

The municipalities are in charge of organising all Finland's healthcare services. They have either formed cooperatives to produce and provide these services together, or they can have them provided by the private sector.

Primary health care is provided in municipal health centres. Every municipality has to belong to a hospital district, but has the ability to choose which one (changes are rare). Employers organise preventive care. There is guaranteed access to care, with a delay of between three and six weeks depending on the type of illness. "We are paying 16-25 cents on every euro on health, depending on which municipality we live in and depending on the industry there." ... "Client charges provide about 5-10 % of the costs."

Secondary health care is also tax funded by the municipalities. Each municipality is required by law to belong to a hospital district. Hospital districts are part of the public system and are owned by the municipalities. In addition, state revenues are given by the central government to municipalities and can be used for primary or secondary care or something that is not health care at all, i.e. the funds are not ear-marked. They are based on the size of the population, the number of employees, and the specific regions. The municipalities can decide what they wish to do with these funds: they can use the funds to build either "an ice hockey rink or a care centre". For example, with regard to secondary care, the municipalities can decide whether they will use the municipally owned hospitals or whether they will purchase care from private providers. However, most of the municipalities mainly rely on their own hospital district for the majority of their specialised care. Research and education funds go directly from the state to the university hospitals.

Four out of five **health services are provided publicly** in Finland, whether this is in terms of personnel or general costs. The situation is somewhat different in some areas of social care, where municipalities purchase many services (like homes for the elderly) from private providers instead of providing their own public provider organisations. So, for the citizens, the social care services are viewed as public services while they are nevertheless produced by private providers.

Thus – while private social care is everywhere – **private health care is available in all urban areas and most particularly in the** bigger cities, for example, in the capital, Helsinki.

2.1.3 Changes in government programmes

In Finland, **social care and health care often work closely together** at both the Ministry and municipal levels; this may even be described as being "integrated". The focus is ultimately on the **client**.

The **current government programme** of Finland's Prime Minister, Jyrki Katainen, dated 22 June 2011, has a strong focus on high-quality and effective social and health care services.⁴ However, Finland is now "really at the doors of a huge change in social and health care" complete with municipal reforms and decisions on exactly how services are provided.

The Ministry of Social Affairs and Health of Finland is especially involved with upcoming challenges and changes. At the beginning of March 2013, the Ministry of Social Affairs and Health of Finland was to receive reports from five Finnish regions offering **proposals for what health care will be like in Finland in the future**. Indeed, after the peer review visit, on 19 March 2013, an expert task force delivered a report to the Finnish Minister for Health and Social Care⁵.

2.2 COMMENTS AND OBSERVATIONS

In terms of health organisation and financing of the Finnish health and social care system, the visiting expert peer reviewers' comments fell into three main areas. These related to the Finnish commitment to equality of access to health and care, the use of diagnosis groups, and the future potential of adding a number of performance measures.

First, the relationship between the **commitment to equality** in Finland, in terms of equality of levels of diagnostic procedures, therapies and health outcomes (as opposed to simply equal rights to access to the healthcare system), was of interest to the experts present. Questions were posed particularly with regard to the quality of health care and its outcomes, and results for people resident in remote parts of the country. Finland is apparently currently exploring this particular challenge, especially with regard to small, isolated hospitals. So too are its neighbouring countries, Denmark and Sweden.

Second, considerable attention was paid to the way in which **diagnosis groups** are used in Finland's health system. In some geographic locations, for example the Helsinki area, diagnosis groups are used to influence the payment system. However, the Finns use diagnosis groups largely as a means of benchmarking and analysis rather than as a way in which to fund specific areas of healthcare.

Third, enquiries were made with regard to Finnish **performance measures** in the health care field vis-à-vis such items as waiting times for hospital access, and the effect that this has both on health outcomes and on patient satisfaction/perception of quality. The Finnish authorities are developing quality indicators, which would detect any considerable differences among health service providers with regard to the services delivered and outcomes achieved for patients.

Finally, a number of general, **clarificatory questions** were posed around the cost and organisation of services, particularly relating to the way in which the healthcare component of GDP is calculated in Finland; the country's distinction between acute care and emergency care; its focus on public sector care; the percentage of private care available; and the way in which general practitioners act as gatekeepers for referrals between the Finnish primary care and secondary care levels.

⁴ http://valtioneuvosto.fi/hallitus/hallitusohjelma/pdf/en334743.pdf Accessed 27 March 2013

⁵ <u>http://www.helsinkitimes.fi/finland/finland-news/domestic/5728-experts-find-common-ground-on-health-care-reform.html</u> 19 March 2013 Accessed 27 March 2013

3 POLICIES, GOVERNANCE AND LEGISLATION

This section covers the Finnish eHealth and welfare policies and governance. It does so against the background of input from both the Ministry of Social Affairs and Health of Finland and the THL.

3.1 INTRODUCTION BY THE FINNISH DELEGATION

Päivi Hämäläinen, Head of Department (THL) and Anne Kallio (Development Manager (MoSH))

cf. doc	Fin Peer Review Day 1-3 Päivi Hämäläinen Governance eHealth and
	eWelfare.pdf

3.1.1 Background from the perspective of the ministry

There are many **different overlapping policies** in Finland. Previously, Finland did not see information society policy as a single strategy or programme. Between 2002 and 2007, many different developments were taking place inside various Finnish governmental programmes. Indeed, according to its officials, if Finland were to have started its initiatives with information technology (IT) from scratch today, the country would not have acted in the same way as it did in the past.

For the Ministry of Social Affairs and Health in Finland "**the elephant is big**" – the challenge of implementing eHealth is a considerable one. Changes in legislation often need to be undertaken to modify an existing implementation timetable, e.g., with regard to ePrescriptions and structured data. Improving an existing system is difficult. Standardisation work is especially demanding. Big challenges remain such as making databases simpler, auditing the various systems, and handling data in registries. On top of this, in their everyday lives health professionals are accustomed to handling very usable information systems, and they have similar expectations of the software that they want to use in their professional contexts.

Today, with regard to **eHealth**, the Finnish health authorities report that they are asking themselves such **questions** as:

- How is "open data" relevant to the Finnish national repository?
- Is information exchange feasible between KanTa and people's personal health records?
- What happens if data is sold on to a third party or a company
- Can usability and process support be guaranteed in terms of electronic medical records (e.g., with both official data and also patient-entered data)?
- Is it possible to shift from available data and information to knowledge management?
- Can health professionals actually be satisfied with IT?

3.1.2 Background from the perspective of the National Institute for Health and Welfare

In historical terms, Finland has been moving from a situation of islands of information systems to **a more systematised approach**. This systematic approach is aimed at creating incre-

cf. doc Fin Peer Review Day 1-4 Anne Kallio National eHealth and eSocial development in Finland.pdf

mentally **a potentially somewhat unique situation** in European terms. While it caters for flexibility at a local level, it creates a highly structured and centralised information repository – constituting lifelong electronic health records for all Finnish patients. All service providers and suppliers must contribute and conform to this system.

In the 1980s, people involved with the health system in Finland started to develop local electronic patient records. Finland has had an official **eHealth strategy** since 1996: it contains a large number of details which would still be relevant today. It necessitated experimental legislation which permitted the sharing of data.

Finland has been working on **eSocial services** since 2004. However, the country does not yet have any legislation on it, and the work has so far not moved towards an implementation phase.

In 2006, a political decision was taken to develop a national IT architecture.

In 2007, the **Finnish National Archive of Health Information (KanTa) legislation** was passed. As a result, the Social Insurance Institution of Finland (Kela) – given its long tradition of trust in Finnish society – was selected as the hosting organisation and technical provider for the new digital services to the whole of Finland.

In 2010–2011, the very first **ePrescribing and eArchiving trials and pilots** were run: some municipalities tested sending data into the archiving systems. It generated a volume of complaints on the part of physicians (who found it complicated to extract data out of the system, since the information is scattered – depending on where the patient visits the general practitioner or the hospital).

In 2011, new legislation was formulated which permitted – inter alia – **patients to opt out** of the system. This new solution is much easier to handle than the obligatory opt-in foreseen in the former legislation (2007). Nevertheless, the manifold updates defined by the 2011 legislation imply many changes to be made to IT systems and have thus slowed down the implementation of the full approach a little, which is being introduced by the OPER unit in the National Institute for Health and Welfare (THL). It is described in more detail below.

The earlier legislation (2007/2011) defines the organisational and structural framework of the new services, i.e. the national lifelong electronic health record system (eArchive). In addition, the Decree on Nationwide Health Care Information System Services (decree 165/2012) defines the key milestones for the data to be entered, i.e. it prescribes **when** each part of the medical records should be entered into the national archive service.

The seven main elements of the Finnish eHealth architecture design are:

- Shared structured (standardised) electronic patient records
- National eArchive for the electronic patient records
- Central consent management
- > eAccess for the patients
- > ePrescription system (in operation in public health care)
- Patient Care Summary
- Information Management System (a new element which was added in 2011).

The data milestones are included in decree (165/2012). They include the times at which various types of content are to be included in the archive. The milestones are 1 September 2014, 1 September 2016 and "after 1 September 2016". They are demonstrated by figure 1 below.



Figure 1: The content foreseen to be "e-archived" at the milestones 2014, 2016 and after 2016 [Source: PowerPoint presentation on 27 Feb 2013 by P. Hämäläinen and H. Virkkunen, cf. section 8]

Until the KanTa system is in full operation, patient data exchange will take place in a "business as usual" way on a regional level, but with no national data exchange possibilities. After **spring 2014**, when **upcoming legislation** has been introduced in Finland, patients will be able to visit and use services in other hospital districts. This will certainly necessitate patient data exchange.

The **S-curve model** (cf. figure 2), indicates the levels of readiness, intensity, and impact that Finland has reached with its eArchive, ePrescription, and eSocial Services applications.



Figure 2: Three of Finland's applications portrayed according to an S-curve model of technol ogy adoption [Source: S-curve model for technology adoption with evaluation focus in different phases

(OECD 2005, p223, adaptation by Päivi Hämäläinen]

Of some importance is the capacity to build a set of indicators that measure capacity-building, the means to change processes, the means to promote care outcomes, and the means to measure impacts on both patients and the healthcare system (cf. table 1 below).

Table 1:Measuring the deployment of Finland's eHealth system – possible indicators[Source: PowerPoint presentation by Päivi Hämäläinen on 26 February 2013]

Types of indicators	Tools/ capacity building	Means to change processes	Means to promote outcome of care	Impact on the patient and the health care system
Examples from the Finnish survey	 Use of EHR Availability of PCs Computer literacy Standalone hospital information systems Digital dictating Access to internet Privacy, security, consent, identifiers Networks Use of standards and codes Budget of health ICT 	 Teleradiology eReferrals eDischarge letters ePrescription eLaboratory Patients access to EHR and secure communicating Electronic booking Web sites for patients 	 Sharing patient summary or whole EHR Decision support tools Telemonitoring Personalized patient portals 	 Changes in cost of health care Changes in provided care Quality, access and cost effectiveness Changes in care outcome (of chronic illnesses) Level of patient safety User satisfaction

3.2 COMMENTS AND OBSERVATIONS

Here the comments and questions posed by the European eHealth experts can be classified into two fields: the first is related to the Ministry of Social Affairs and Health, and the second is concerned with the Social Insurance Institution of Finland (called Kela).⁶

The general eHealth approach appears to be **long-term**, **incremental**, and sufficiently **flexible** to be adaptable to changes. It has been modified several times over the lifetime during which it has been operational. In terms of these high-level changes to the Finnish health and social care systems, a certain number of comparisons were made with similar policy-related shifts in direction e.g., in the **Swedish healthcare system**.

The peer reviewers perceived the need to see the "**big picture**" in terms of changes being proposed to the Finnish health and social care system and the **strategic benefits** that would be achieved. It was felt that a focus on the **underpinning policies** behind the technological and organisational tools was needed.

The Finnish authorities were encouraged to consider a shift from data to information and, ultimately, knowledge.

At times, however, the visiting peer reviewers found it difficult to understand the **ultimate purpose** why data is being shared, e.g., in terms of supporting clinical pathways or enabling new process of care.

The precise **motivations and incentives** of the three main health stakeholders (e.g., decision-makers, healthcare professionals and management, and patients) for using KanTa will

⁶ http://www.kela.fi/in/internet/english.nsf Accessed 27 March 2013

need to be borne carefully in mind. For example, if the plan is to evolve towards **integrated care**, there will need to be clear definitions of roles and responsibilities. Equally, the peer reviewers considered **governance and surveillance** issues to be important.

It was clear to the peer reviewers that changes in the Finnish health and social care system would affect substantially the **work of Finnish healthcare professionals**, and particularly the roles of clinicians. Nurses' roles too will be subject to modification. Any shift towards **patient ownership and patient management of data** is likely to modify the doctor/patient role(s).

Organisationally, the question was raised about what were **the appropriate organisations** in the Finnish system to oversee, operate and further develop the KanTa services in the longterm.

The degree to which there had been **public debate and dialogue** on all of these matters was also of interest to the reviewers.

There were also three sets of diverse questions with regard to the **degree of centralisation** of the approach chosen by Finland, the choice of information (IT) systems, and finer – often systems, organisational, or technical – details with regard to the system itself.

First, there was also curiosity about why the neutral term **eArchive** had been chosen for a life-long electronic health record system. The peer reviewers later suggested alternative phrasing for this "archive" (see sections 8 and 10 of this report). Second, they queried why **a centralised approach** to the design of the system had been used originally. Third, they wondered about the range of **choice of IT systems**. In fact, at least seven IT companies are contracted to individual municipalities in Finland. Fourth, a number of clarificatory questions were posed about **the system, and its organisational and technical details**. These covered the actual location of the "archiving" system – a large computing centre – in Kela, its relationship with cloud computing, and the expected length of time of data storage (i.e., for the duration of a person's lifetime, plus 12 years following death). In Finland, in addition, the personal data of people born on particular days of a given month, is kept "forever" for longitudinal research purposes). There were also queries about the length of time since the national "archiving" system was developed, and its principles with regard to opt-in and opt-out measures.

4

FINNISH NATIONAL EHEALTH ARCHITECTURE AND ITS EXTENSION TO SOCIAL CARE

KanTa denotes the Finnish national eHealth architecture of which the core infrastructure has been implemented. KanSa, the extension of this architecture to Finnish social care, is in planning phase.

The **National Institute for Health and Welfare** (THL) has 1,200 personnel. OPER is its unit for the operational management of health and welfare information in Finland. This presentation was made from the perspective of its head, Dr Vesa Jormanainen. There are 20 persons in the OPER unit, and staff members have and come from different backgrounds, disciplines, and communities.

4.1 INTRODUCTION BY THE FINNISH DELEGATION

> Vesa Jormanainen, Head of OPER Unit (THL)

cf. doc Fin Peer Review Day 1-2 Vesa Jormanainen eHealth architecture KanTa extension KanSa.pdf

Planning and analysis for the national **eHealth architecture** started in 2010, and involved an examination of past progress. This investigation was viewed as important for planning purposes. The approach focused on both on the **professional user needs** and the **administrative and healthcare demand side** of health-IT systems. The user side comprises various domains of professionals (with many actors playing several different roles).

Finnish physicians work, at the same time, in both the public and the private health care systems. Thus, in their work, health professionals have to use **many different systems and interfaces** in their workplace, depending on the actual patient with whom they are dealing and the IT-system of the care provider. They may even have to use two or more interfaces for the same client. Certainly, physicians need currently to learn to use new systems or new items of software. Indeed, there are between 15-20 different major systems in operation throughout Finland.

The Finnish health and social care system can be described as one of "the world's most decentralised health systems", which is quite widely geographically "scattered". As a result, a considerable diversity of IT systems are used. This raises **the risk of sub-optimisation of provision and care**, e.g., when patients travel from place A to place B and where different IT products or solutions are used.

A total of seven different electronic health record systems are used: Five in public primary care and four in public hospital-based specialised medical care (while two systems are used in both settings). Local decision-makers have been able to use their influence with regard to the choices of system and IT equipment that they have made.

All the different electronic health record systems in the primary sites (in both primary care and hospitals) will be connected to the national infrastructure. A network view of the system architecture is provided in figure 3 below. For a complementary view on the systems' services, demonstrating the data flows and building blocks, please refer to figure 9 in section 7 (standards) of this report. As already mentioned, the KanTa system will also function as a technical basis and an architecture model to support social care (KanSa).



Figure 3: Network view of the KanTa architecture [Source: Marko Jalonen, Kela]

The system consists of both **a central part** – which is ready to use – and other more **decentralised components** to connect to primary systems at the healthcare sites.

The **investment cost** for the central system has been 35-38 million. The decentralised element of the system is, however, not yet ready. Costs have been calculated for the ten-year, 2004–2014, time span. In 2010, the cost estimation was of 200 million for the full KanTa system – comprising 100 million for the central system, and $\Huge{100}$ million for all the partners needing to join (including private partners).

The first components of the eArchive have been in operation for some two years already.

ePrescription implementation started in 2007 and the first organisation started to use ePrescriptions in 2010. The plan for deployment of ePrescription take-up has been based on hospital districts. The current situation is discussed in detail in section 6. Nearly 70% of prescriptions from the organisations that have joined are electronic, but the total national figures are much lower because the private sector is not yet involved.

In 2010, a European Commission study was undertaken and published in 2011, on eHealth benchmarking in acute and secondary care.⁷ It investigated the status of IT use in all 27 European Union member states as well as Croatia, Iceland and Norway. Finland has assessed its own status independently: it used a similar **measurement system** to this 2010–11 study to investigate its own usage of eHealth.

This **assessment** shows the country's use of various applications to be higher generally than the European mean in both primary health care settings and in secondary care. The exceptions

⁷ European Commission (2011) *Benchmarking eHealth Deployment in Europe*. eHealth Benchmarking III. Deloitte & Ipsos Belgium.



in specialist health care are ePrescription (which was therefore lower in 2010), and 24-hour access to administrative data.

Finland in an International Comparison:

Figure 4: Finland in an international comparison - primary health care, situation of early 2011. [Source: Unpublished preliminary data by Reponen J, Kangas M, Winblad I, University of Oulu, FinnTelemedicum]







[Source: Unpublished preliminary data by Reponen J, Kangas M, Winblad I, University of Oulu, FinnTelemedicum]

Finally, what work is planned for the OPER unit between 2011–2016? The main foci, in alphabetic order, are **eAccess for citizens**, an **eArchive**, **ePrescribing**, and the **patient care summary**. The systems have started to be implemented on certain installation sites.

Timetable 2010–2016

					Fallent	Directive	implementatio
		OPER					
	2010	2011	2012	2013	2014	2015	2016
ePrescription		(31.03.2011)	31.03.2012	31.03.2013	31.03.2014		
Pharmacies: obligatory to connect Public Health Care: obligatory to connect Private Health Care: obligatory to connect	19.05.2010 20.05.2010		31.03.2012	31.03.2013	31.03.2014		
eArchive		(31.03.2011)			31.08.2014	31.08.2015	
Public Health Care: obligatory to connect Yksityinen th: obligatory to connect		15.11.2011			31.08.2014	31.08.2015	÷
eAccess for Citizens		(31.03.2011)					
ePrescriptions: eAccess service open for use eArchive: eAccess service open for use	19.05.2010	15.11.2011					÷
Patient Care Summary for Healthcare Professionals					31.08.2014		31.08.2016
Phase 1: obligatory Phase 2: obligatory					31.08.2014		→ 31.08.2016

Act on Health Care 2nd Phase

Figure 6: OPER timetable 2010-2016 [Source: Vesa Jormanainen, THL]

4.2 QUESTIONS AND OBSERVATIONS

The peer review experts were particularly interested in the **governance**, **financing**, **and organisation of the eHealth architecture system**. For example, their questions related to whether the entire system had been developed using public funding, and what precisely the investment cost had covered.

The **change management** system, and how health professionals have been encouraged to adopt the system was viewed with some interest, as was the system by which local decisionmakers can select particular electronic tools. Scotland, it was noted, for example, holds centrally a framework list of key systems for primary and secondary care from which the local health organisations can choose. Agreements have been reached in Scotland with the regional health boards to converge on a strategic set of clinical and administrative systems.

A number of questions posed by the reviewers related to **legacy systems** and how they are handled, and whether the fact that the systems have been modified over time has posed difficulties (or not). Whether the Finns are working on **certification** was also of interest. Some of the reviewers questioned the feasibility of having **so many IT system suppliers** that are able to modify their systems in the desired timeframe so as to exchange data in the standard forms specified.

The peer review experts queried the manner in which the electronic medical records have been built, and their implications, for general practitioners, in terms of **work organisation and ergonomics**. Electronic medical records standards could contribute positively to the **evolution and certification of systems**. Section 7 of this report on standardisation expands on these concepts.

Since there appears to be such a large amount of data monitoring in Finland, several questions about **access and retrieval** were posed.

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5 PATIENT AND CITIZEN ESERVICES IN HEALTH AND SOCIAL CARE

5.1 INTRODUCTION BY THE FINNISH DELEGATION

- Minna Angeria, Project Manager (THL)
- Jari Suhonen, Project Manager (THL)

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cf. doc Fin Peer Review Day 1-5 Minna Angeria - Jari Suhonen SADe Patient and
Citizen eServices.pdf
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Plans and strategies for using IT for social welfare and health care have existed in Finland for nearly 20 years. The overarching goals are to improve and increase:

- the availability, quality and efficiency of social welfare and health services,
- clients' independent initiative and participation, and
- health awareness and empowerment of the clients.

With regard to health and healthcare, this part of **Finland'scitizen eServices (SADe) programme** has its focus on two elements, i.e. to define and provide digital means to foster citizens' participation and the development of electronic services in social welfare and health care.

In the framework of the peer review, the emphasis was on **citizens' and patients' access to their health data and services** in the KanTa framework. The third part of the triangle (cf. figure 7) on the National development for eSocial Services (the former Tikesos project) was not further detailed.



The SADe program is driven by the Ministry of Finance in co-operation with other ministries. The Ministry of Social Affairs and Health is responsible for the social and healthcare part of

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the SADe project. So far, SADe-related services are offered on **a voluntary basis by municipalities** to their citizens. There is thus a huge difference between SADe and KanTa (which is compulsory by legislation and is being rolled out nation-wide). In the long run, the development of healthcare legislation is geared to further strengthening the client's position as is evident in the recent Finnish Health Care Act. The full "Action Programme on eServices and eDemocracy" (SADe) is financed for the period 2009-2015 by the Ministry of Finance. It promotes citizens' eServices in some non-health-related fields of society too.

The Patient Access services in KanTa:

The eServices for Health in KanTa foresee **patient access** (*eKatselu*) to various services, particularly electronic prescriptions (drug purchases, prescriptions, printed summaries of prescriptions, and user log records) and electronic health records (diagnoses, imaging data, laboratory results, medication data, referral and discharge information, and treatment periods).

The security infrastructure of the service provides strong **electronic identification** for all users. The users log in either by using Internet banking IDs (nearly all adults in Finland have this) or national eID cards (these are smart cards with certificates), which are used less frequently. An extension supports the use of digital certificates for health professionals. The services are hosted and maintained by the Social Insurance Institute of Finland (Kela).

The access to personal health data is also used to manage **consent** in the KanTa system. When consent is given (via an opt-in), 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**.

Finally, the patient access system is used to register organ donation, wills, and living wills.

The SADe programme:

In the SADe programme there are other themes addressed by the Finnish service portfolio for the social and health sectors to promote the health and welfare of families with children and prevent social exclusion. For example, they are oriented towards both children and older adults. On one hand, this includes the prevention of child obesity, inactivity, and excessive playing of computer games. On the other hand, it promotes the health, welfare and capacity of elderly people, e.g. by preventing memory disorders, and falls.

The **long-term vision** is to help citizens to take responsibility for their own well-being and prevent various health problems. It is intended to do this by using the Internet as the citizen's personal trainer. This will involve the use of virtual medical examinations, personal data to create instructions, or the provision of treatment programmes that promote health and well-being. It will also encourage citizens to follow instructions and offer them rewards in terms of the positive monitoring of follow-up and results. A virtual service instructor would guide a citizen to the appropriate service provider on the basis of the need for service, quality, and comparative data.

5.2 QUESTIONS AND OBSERVATIONS

Patient consent was the first issue addressed by the European eHealth experts, i.e., whether the use of electronic health records can be refused by patients. This option is no longer possible in Finland, since the use of paper records has been discontinued. Yet a patient could refuse the sharing of his or her records by one health care provider with other health professionals. In any case, the acceptance of the Finnish population for both KanTa and the healthcare registers is quite high.

The granularity of the **access management** allows a patient to refuse the sharing of data related to a particular encounter with healthcare providers. A patient will of course receive explanations on the risk that can result from this opt-out. As in other European countries, access rights to patient data are based on the "need to know". In practice, contact with a health care organisation legitimates a three-month access period – respecting, of course, any existing optouts. Special rules are applied for data related to psychiatric diseases.

Usage of any health data is by legislation limited to healthcare (treatment) and health surveillance.

Responding to an expert's question, the point was also made that **patients' access to their health data** (cf. the eAccess element in KanTa) is about to trigger a change of behaviour in healthcare providers way of documenting appointments and diagnoses. Indeed, Finland can already observe groups of healthcare providers that are starting to discuss their documentation approach.

The European eHealth experts also asked questions about the **use of smart cards for health professionals**. The main benefit of using cards seems to be the support for physicians working in different settings as part of their daily routine. A nation-wide defined system of card certificates eases the process of adhering to permissions based on the professional role and the work (healthcare) context. Future technology changes may enable updates to the current system, i.e., using banking cards in Finland for other health-related purposes and introducing new, mobile technologies. Adding or changing technologies must then also involve alternative methods for signing electronic prescriptions: currently the use of smart cards with physicians' certificates is binding for the issuance of ePrescriptions in a legally valid form.

6 USER ORGANISATION PERSPECTIVE

6.1 INTRODUCTION BY THE FINNISH DELEGATION

Maritta Korhonen, Development Manager (THL)

cf. doc Fin Peer Review Day 2-4 Maritta Korhonen User Organisation Perspective.pdf

The inclusion of **professional users' perspectives and requirements** was described using the setting of the Finnish ePrescribing service.

The focus was on the **public and private sectors** from the perspective of **two sets of stakeholders**, physicians and IT management. The facts and figures cited were totally up-todate; they were taken from meetings held in the largest areas of Finland on February 4, 2013.

ePrescribing use differs among the various areas of Finland. The system has developed substantially over the past three years between 2010-2013. In March 2013, on average in Finland, 66% of regions are using it.

Data on a total of 50,000 new prescriptions is fed into the system every day; the **volume of prescriptions** is growing at least along the same lines.

At present, the organisations and individuals using ePrescriptions appear to be quite satisfied. This is due largely to the degree of joint **planning** that has been undertaken in the system's implementation. The country has an action plan that covers implementation, piloting and auditing, and implementation. It shows – at each stage of activity – what will happen next in terms of implementing ePrescriptions.

This **systematic approach** is very much appreciated within Finland, and is viewed as being especially of assistance to the private sector and the IT vendors. Planning meetings are currently being held in which the healthcare organisations and the vendors meet together, thus enabling them to cooperate. The strict planning timetables are also viewed as good for the health organisations involved.

A **number of risks** were, however, perceived. They related to specifications, timetabling, usability, and acceptance of structured documentation. Finland's answers to the management and mitigation of these risks have included **two plans**: a clear testing plan and an implementation plan. Cooperation with users and vendors has been developed, and there has been concentration on the development of appropriate guidelines and training.

As of February 2013, the views of clinicians and IT management vis-à-vis ePrescribing were quite positive. These have been identified by the Finnish authorities as:

From the doctor's viewpoint: On the one hand, ePrescriptions are always readable, easily locatable, and cannot be falsified. ePrescribing is faster; there is no need for the use of phone calls. All of a patient's medication can be seen in one place. Patient safety is therefore improved. eAccess is a possibility on the patient's part, which leads to patient empowerment.

On the more technological side, both the technology and the software work well, and now provide tools for cooperation with primary care, secondary care, and pharmacists. As one doctor has said, "[This is] a huge step exactly into the right direction."

From the IT management's viewpoint. There is a good action plan, schedule, and guidelines. The new services are useful, and there is increasing use of both national services and national specifications. This initiative develops a good comfort level with new ways of cooperating. It is helping to develop "a culture of project work". It also encourages an understanding of the importance of data integrity.

Overall, health care providers desire a **national architecture and clear leadership**! This level of direction is expected from both the Finnish Ministry of Social Affairs and Health as well as from the National Institute for Health and Welfare, including OPER.

Of course, some critical questions remain as to whether there is **sufficient time and money** available to achieve all the plans that have been set out. These are issues which need to be addressed.

6.2 QUESTIONS AND OBSERVATIONS

The European eHealth experts had a number of questions and observations that fell into several categories: the relationship of the Finnish situation with the international context; the business side of implementation and incentives/motivation; the technology solutions sought; and the opinions of physicians, pharmacists, and patients.

International and national levels: Two sets of questions were explored. The first set was the benefits of getting involved with **European Union-level initiatives** (and international) around ePrescribing, such as engagement in the epSOS, large-scale pilot initiatives.⁸ The second was the extent to which **Finnish society itself is benefiting directly** from the shift towards new eHealth services like ePrescribing.

Organisations and users: The ways in which, in addition to more obvious large international corporations, **smaller-scale organisations** such as small- and medium-sized enterprises could enter the national service were discussed. There was a brief examination of the **methods used to motivate users** to join the system e.g., through changes to the legislation, diverse forms of social control, and tight project management and timetabling.

Technology: On the technology side, the existence of **cloud-based solutions** were queried and the way in which this can be attractive for such occupations, professions, and organisations as e.g., nurses, occupational therapists, and small private health care organisations (here, the example of Belgium was cited). A number of items were also explored with regard to frequency and regularity of **software updates** and various methods of managing this (examples were again cited by the Belgian eHealth expert) as were the benefits of having external service releases with scheduled and planned approaches (e.g., in the case of such international products and services offered by the Mozilla Foundation).

Physicians, pharmacists, and patients: A number of issues in the ePrescribing field were of keen interest in terms of questions surrounding hospital pharmacists and clinicians. There is considerable value to the **continuous updating of information towards prescribers** when prescriptions are collected at pharmacies (dispensation), since this enhances **patient compliance** and optimises drug related plans and decision making. While such updates would be delivered via the ePrescription server to the health professionals there would be an added value for a separate list of drugs to be collected by patients at pharmacies (see the ensuing commentary on comprehensive medication lists).

Several questions were posed from the perspective of a **pharmacist**, whether this was as a hospital pharmacist or as a community pharmacist on the high street, e.g., the availability, within the ePrescribing system, of a **comprehensive medication list** that could include over-the-counter or non-prescribed drugs, and natural products leading to counter-reactions.

The specific linkage of the ePrescribing application to **patient health records** was also explored, as well as any association between the Finnish National Archive of Health Information (KanTa) and patient health records. It was felt strongly that **patients** should also be active contributors to the whole process.

⁸ http://www.epsos.eu Accessed 28 March 2013

7 THE USE OF STANDARDS

This section covers the Finnish standardisation process, starting out with the solutions chosen or implemented and their relationship with international interoperability standards.

7.1 INTRODUCTION BY THE FINNISH DELEGATION

- Konstantin Hyppönen, Kela (The Social Insurance Institution of Finland)
- Marko Jalonen, Kela (The Social Insurance Institution of Finland)
- Jari Porrasmaa, MoSH (Ministry of Social Affairs and Health)

cf. doc: Fin Peer Review Day 2-1 Jalonen Hyppönen Porrasmaa KanTa_Standards and Interoperability.pdf

This joint presentation by Kela, the Social Insurance Institution of Finland, and the Ministry of Social Affairs and Health provided an overview of two aspects of standardisation in Finland. First, it covered the **history and timeline** of Finnish Healthcare ICT Standardisation, Standards and infrastructure services applied in the current National Healthcare ICT System Architecture. Second, it showed how **standards are managed**, e.g. deriving localised standards and organising testing and approval processes. Against this backdrop, the participation of Finland in the European epSOS large-scale pilot on selected cross-border eHealth services was seen as an interesting test case for the robustness of the interoperability enablers in the Finnish system. Figure 8 (next page) demonstrates the long and **systematic planning and implementation** around standards since 1995, the year of the foundation of the HL7 user group for Finland. By 2008, Finland had launched a National Special Interest Group around the Integrating the Healthcare Enterprise (IHE) context and plans to approach IHE officially in 2013. Finland has meanwhile founded a full national chapter of the IHE organisation (the contact person is Jari Porrasmaa, one of the presenters, who works at the Ministry of Social Affairs and Health, and is hence in a key position for planning purposes).



Timeline of Finnish Healthcare ICT Standardization for Interoperability

Figure 8: Timeline of Finnish Healthcare ICT Standardisation for Interoperability [Source: Konstantin Hyppönen, Marko Jalonen and Jari Porrasmaa]

Figure 9 (next page) provides a comprehensive view on services, interfaces, documentations and standards of the **Finnish eHealth infrastructure**.

It becomes evident, even through a quick glance, that the national architecture has been developed completely on the basis of **well-accepted international standards and profiles** like HL7 v3 (including CDA R2, W3 XML for digital signatures and a x.509 certificate based infrastructure for the ISO 7816-* compliant smart cards). DICOM for imaging and Object Identifiers (OIDs) are also in use. The adaptation of the IHE XDS profile family for crossenterprise data sharing is under development

PikaXML – used for referral-report process automation – is a non-standard XML format, based on the Medcom (Denmark) MEDDIS profile (and is thus an EDIFACT standard).

A notable achievement is Finland's **national code server** which was established from 2002 onwards. Based on the country's longstanding engagement to standardisation, it was noted that **semantically adequate conversions of structured data are possible between Finnish and international profiles.** The KanTa production phase is supported by dedicated testing and approval processes. Finland has **national test cases/patient stories**, and these are continuously developed for interoperability testing.



 Figure 9: KanTa – Schematic View – Highlighting infrastructures services, interfaces and standards
 [Source: Konstantin Hyppönen, Kela]

Konstantin Hypponen, one of the speakers, serves as epSOS technical lead for Finland. The country joined epSOS in 2011. A main goal was to establish a **cross-border ePrescription pilot with Sweden**: The planned pilot accommodates patients in the north of Sweden and Finland (in the Torne valley) who can obtain medicines from both countries. The ePrescription pilot will allow Finland and Sweden to participate in pan-European testing and other work. Finland qualified as a pre-pilot for testing as Country A (ePrescription sender), and it was also getting ready in March 2013 to start testing as Country B (ePrescription dispenser).

epSOS is understood to act as a test-bed for **mapping the Finnish architecture to international standards**. The test is reported as having been successful, with the country having demonstrated a robust standards-based system. Good support infrastructure and collaboration was also noted between the various Finnish national authorities (such as Kela, THL, Population Register Centre, Finnish Medicines Agency, Pharmaceutical Information Centre, and the National Supervisory Authority for Welfare and Health), which can acquire certificates and OIDs easily.

Figure 10 (next page) indicates the way in which the epSOS pilot is connected with the Finnish National Contact Point and, internally, standards are used in the contacts with the various Finnish internal applications, particularly for registers such as ePrescriptions, health-care professionals, and pharmacies.



[Source: Konstantin Hyppönen, Kela]

7.2 QUESTIONS AND OBSERVATIONS

The questions raised by the experts dealt mostly with requests for clarifications. These clarified understandings have already been implemented in the text in the body of this written report.

Among the main observations and lessons learned, the European eHealth experts noted that:

- Finland tries to adopt international standards and to follow what is happening internationally. However, Finland does not go for the freshest initiatives. Rather, it tries to use what is feasible and what is rational. So far, the choices of standards have been generally well-grounded.
- Finnish extensions to standards do not block interoperability. Those extensions that have been adopted are allowed by the standards.
- Within its work inside epSOS, Finland is moving towards IHE profiles. This is currently established via THL and Kela that are jointly undertaking a proof of concept on the case of KanTa. It has been prepared through studies that run in various Finnish universities, funded by the Finnish Funding Agency for Technology and Innovation (Tekes).
- Finland could consider hosting the next IHE Connect-a-thon. This proposal for the next Connect-a-thon has now been taken up.

One particular view was that all **standard development and implementation work should be guided by the priority health problems**. Finland responded that the patient summary is seen as being comprehensive enough to cover all diagnoses and the necessary data for the diagnoses.

There were three further opinions expressed, all related to fine tuning the scope or just the name being used for the KanTa services: First, it was felt that the **eArchive** had been planned as **a largely passive service**. Second, it was thought that it had been designed to work as a

straightforward, albeit extremely large, repository which would hold all the medical records for a single individual in a single place so as to allow access by any provider (and the individual) at the point of care when required. Third, it was considered that it could also be used to support **an active service**, i.e. ,the eArchive could be used as a life-long electronic health record – in other words, it can be an individual **data warehouse for health challenges**. Thus, the act of storing a record in the eArchive could be an event in a series of workflows that could initiate subsequent actions. The eArchive could act as an extremely rich source of analysis allowing the tracking of events and record contents through to outcomes – in effect, revealing a patient's journey through various points of contact and service.

8

STRUCTURED DOCUMENTATION AND TERMINOLOGY WORK

This section covers the Finnish structured documentation and terminology work chosen or implemented from the point of view of the relevant national organisation.

8.1 INTRODUCTION BY THE FINNISH DELEGATION

Päivi Hämäläinen, Head of Department (THL)

cf. doc: Fin Peer Review Day 2-2 P Hämäläinen H Virkkunen Structured documentation - terminology.pdf

Finland has a long tradition in defining life-long, 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 specialised 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. A general practitioner's record was kept life-long within the same health care centre. The same idea of content standardisation was continued with the national terminology and code server. It started to operate in 2004 at STAKES – the predecessor of THL.⁹ Given this reference, vendors have had a considerable time-period through which to get involved in this process, since the relevant information has been around for a long time.

In 2007–2008, there was a revision in the requirements with regard to what data has to be kept in the life-long health record. Additional projects took place in THL during 2009–2011. During the process, it was not clear who had the mandate to define the obligatory standards. Since 2011, however, **THL is entitled to create these definitions on behalf of the health care sector**. It is not yet able to do this for the social care sector, however. The work is led within THL by OPER: OPER defines and implements obligatory structures for health care and recommended structures for social services.

THL is responsible for conducting **walkthroughs of all types of data** to prepare the specifications for data to be stored in the national archive. In the long run, all patient data (including x-rays, i.e. imaging data) will be stepwise subject to specifications that will enable them to be stored in the archive. THL is organising and running many **specialists' working groups** to prepare these specifications. As part of the terminology work, there is also a plan regarding SNOMED-CT, i.e. that Finland will join IHTSDO.

The National Code Server – founded in 2004 – is a key instrument to cross-link and harmonise codes and terminologies that are needed for a reusable digital documentation of healthrelated problems and conditions. Moreover, the terminology server pursues the harmonisation with international coding systems as an overarching aim. This includes the potential use of SNOMED CT as one reference terminology.

Decree (165/2012) defines quite explicitly the content of and the timeline for the **National Patient Care Summary**, i.e., the structured information that is essential to the health administration and the medical treatment of the patient (cf. sub-section 3.1.2 for more detail on the content of the decree):

The patient summary comprises:

[2014] Personal data of the patient including medical notes

⁹ On 1 January 2009, STAKES and another institution merged to form the THL.

- [2014] Procedures and imaging examinations that have been entered using procedure classification codes
- [2014] Laboratory results
- [2014] Diagnoses
- [2014] Information on medical risk factors
- [2016] Medication
- [2016] Vaccinations
- [2016] The most important physiological measurement results entered as structured documents
- [2016] The plan concerning the examination, treatment or rehabilitation of the patient, or other similar plan (national archiving obligatory 2014).

The years 2014/2016 indicate the start-date at which national archiving becomes obligatory.

Four other data sets (cf. figure 1, page 6) to be sent to the eArchive life-long electronic health record in the first phase (obligatory from 1 September 2014 onward), include:

- Expressions of will concerning organ donation, treatment, and the patient concerning his/her treatment;
- Documents of patient's consent and prohibition of the disclosure of the patient records and information given to the patient concerning disclosure of patient records;
- Contact and other personal data of the patient;
- The first part of the patient care summary: diagnosis, procedures, risk factors, laboratory results, imaging examinations, and the health care plan.

8.2 QUESTIONS AND OBSERVATIONS

Discussion among the European eHealth experts and the Finnish team clarified the status of the situation as it is today.

The experts viewed as impressive how Finland has managed to mandate such **a wide set of** actions and standards, and fully expects all organisations (both public and private) to comply with these by the dates specified. Finland is assured that, once requirements have been "decreed" then they must be met which will guarantee that vendors will comply with a post-contract mandate, and by the times required. The Finnish authorities do not anticipate that international vendors may choose to leave the market rather than introduce these changes.

Finland has **a roadmap** that defines the work needed by 2014/16. Some of this work has already started. Content and definitions should be ready about three years before the dates required in the actual legislation. THL is satisfied that it can finalise the work intended for 2014 already in 2013. Some of the 2014 deadlines may, however, be a bit tight.

The various **vendors** have found that the specifications/definitions for work to be done are not precise enough: the specifications need to be re-defined, and there is much minor level work involved. National collaboration on how things are to be done is on-going. Interested health care organisations participate in **workshops** that are open for all the interested parties, including vendors. The formal part of this work is handled by several **clinical and medical groups**. From a recently held survey, THL knows how many primary care centres in districts are working on these issues. For specialist care, the involvement is very high, and all the districts are involved. Primary care has been a little bit less active.

Finland has established **ICD10** in specialist care and most private applications. Some medical domains are much lower e.g., around 30 %. ICD10 is important for: e.g., patient care; scientific research/quality analysis, statistics, and administration. It can be used for regional health statistics and many other analyses.

Using and adapting the relevant international standards, Finland has defined a **clear-cut structure for the patient summaries to be copied to the eArchive life-long electronic health record**. The European eHealth experts understand the patient summary as the ideal basis for **integrated care**. This is supported by the idea of making the treatment plan one part of the data in the central storage. As also suggested by the experts, the plans will in the future be used for **defining workflows**.

Given all this usage in support of active healthcare, the European eHealth experts proposed to update the name of the archive e.g. to "Living Archive", or a name that is closer to the notion of an active, life-long electronic health record. (In making this statement, the reviewers may not have been aware of all the implications of the current Finnish legislation, that also uses terminology like "active health record" or "patient-centric data".)

9 SECONDARY DATA

9.1 INTRODUCTION BY THE FINNISH DELEGATION

Päivi Hämäläinen, Head of Department (THL)

cf. doc	Fin Peer Review Day 2-3a Päivi Hämäläinen Secondary use (1) data
	depositories.pdf
	Fin Peer Review Day 2-3b Päivi Hämäläinen Secondary use (2)
	AvoHILMO.pdf

THL is the national organisation that is also responsible for **health statistics**, e.g. on social and health services, alcohol and drugs, social protection and health expenditure. It organises the registration of the data, analyses it, publishes the data publicly, and interacts with the various responsible international organisations, such as the World Health Organisation. Finland has many different registers, the oldest one being for cancer.

In the context of the expert review, **two registers** deserved special attention since they can support the monitoring of changes to health care 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 (general practitioner-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. This register has been in existence since 2011. If the General Practitioners use the electronic system, data is automatically extracted.

The **AvoHILMO Register** (cf. figure 11, next page) allows to plan, monitor and compare 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 National eArchive of health Information.



Figure 11: The AvoHILMO register receives data via automatic data retrieval in primary care [Source: PowerPoint presentation by P. Hämäläinen]

9.2 QUESTIONS AND OBSERVATIONS

Following this presentation, the eHealth experts present offered more observations than posed questions. Many of the observations were related to processes being undertaken in either other European Member States or at the European level as a whole.

The **data quality** of the registers and corresponding medical statistics is dependent on precise documentation in terms of structured data. **Adequate feedback** on data quality and relevant clinical information can support this goal. **Support of criteria-based documentation** of classifications and procedures in the electronic medical record systems themselves or **the establishment of an integrated rule-based national coding module** could be considered. Norway has, e.g., a strategy of this sort, in which there are plans to implement a criteria-based national coding model with quality indicators.

The use of registers and secondary data stimulated a lively discussion, e.g., on **linking registers** for research to check the completeness of the linked registers or to set up "joined registers".

Registries can offer support to **target health care to those who are really in need of it**. The focus should be on patient registries that are close to patient records, e.g. in the form of adjusted clinical groups (ACGs); and to manage healthcare management. According to the **2005 Luxembourg declaration on patient safety**,¹⁰ registers should also set up to record medication errors. In France, hospitals record all adverse events in relation to medication.

The legislation for Finland foresees that in future all the **purpose-specific registries** will be fed from the eArchive (cf. the AvoHILMO example above). The new documentation system will also account for an updated HILMO data structure. THL would already like to **organise**

¹⁰ <u>http://ec.europa.eu/health/ph_overview/Documents/ev_20050405_rd01_en.pdf</u> Accessed 27 March 2013

the registers more efficiently. It believes that the best approach would be to set up a single register that would combine the data in all the other registers.

However, **Finnish legislation on registers is very strict**: combining the data sources would only be allowed in order to produce specific health statistics. While the "EHR 2015" dataset would hold all the necessary medical data for a single multi-purpose register, **this data will not be sufficient** for the envisaged multi-purpose register since additional organisational data must be sent to the registries.

Work may also be needed on **pseudonymisation** to comply with the upcoming European regulation on data protection that may require Finland to institute more privacy and data protection vis-à-vis its citizens/ patients.

On a more general note, the reviewers were also interested in learning what **benefits or outcomes** would be delivered through each of the phases of work described. Although the capabilities that would be delivered were explained, **the benefits that would be achieved from them were not covered in any detail**. This raised the importance of the topic of **measurement**, and **performance and quality indicators**. Despite the impressive demonstration of reporting systems – like AvoHILMO – it was not clear how the Finnish authorities will achieve evidence on e.g. efficiency savings from the high levels of investment that have been made (for example, for ePrescribing cf. section 6 of this report).

10 SUMMARY OF EXPERIENCES AND LESSONS LEARNED

SWOT ANALYSIS



This section draws on the feedback captured in the concluding session of the EHTELconnect peer review workshop. The section reflects on the various circumstances experienced by Finland in terms of its health and social care systems. The list of observations from the different peer experts attending the meeting have been categorised according to a SWOT analysis¹¹ framework (strengths, weaknesses, opportunities and threats). Proportionally speaking, far more strengths and opportunities were perceived than weaknesses and threats, i.e. a set of issues or questions that might be considered by the Finnish authorities in more detail.

Overall, the expert peer reviewers valued greatly the visit and its content, and the opportunity to learn more from the Finnish context.

Finland has been involved in **long-term development** of its eHealth systems and services, developing from a mainly localised approach towards a more national-level approach that maximises the benefits of local ownership and flexibility, but operates it within an overarching structure of information sharing and standardisation. Finland has managed to track its eHealth work systematically over time. Hence, its authorities are able to see clearly the trends that have developed over a broadly 30-year period. The basic **openness, trust**, and **transpar-ency** apparent in this particular Nordic country makes it a very helpful setting in which to develop eHealth systems. There has also been an impressive degree of **regionalism and local** "**democracy**".

Finland has quite early introduced digital documentation and health care became paperless in many domains. While the "first generation" tools have now reached their limits, Finland has to move to a next generation of services. Here again, Finland has the opportunity to be an early adopter of current concepts and methodologies.

There is one limitation on the "level of observation" to be kept in mind when reading the SWOT analysis: Overall, the presentations made were considered by the peer review experts to be comprehensive and detailed. However, they could have been improved in two areas. First, throughout the series of presentations, **no precise "case studies"** were discussed in any detail. Second, there were **no presentations from senior clinicians or more local operational managers** (such as domain experts and champions) who could present the actual purposes underlying the substantial investments made in terms of either operational or clinical outcomes.

10.1 STRENGTHS

In terms of its strengths, Finland was praised for the following:

World-level: Finland is at a world-level benchmark in terms of eHealth.

Compelling vision, strategic change, and appropriate legislation: There is a strategic change programme occurring in Finland that provides a compelling vision of integrated

¹¹ The drawing has been extracted from an article on Wikipedia on SWOT analysis (http://en.wikipedia.org/wiki/SWOT_analysis)

healthcare. It has consisted of two parts. It is in part a legislative programme, to meet the challenges of societal change and financial pressure, and in part, an imperative for modernisation so as to meet the expectations of health workers and citizens.

Health and social care together: Finland's way of bringing health and social care together provides an excellent setting for other countries to start thinking about their own re-design of the social and health care system.

Two sub-systems are particularly impressive: they are the ePrescribing initiative and the registries/secondary data collections: ePrescribing has a long history in Finland, and there appears to have been some important progress in this field. Overall, the quantity, timeliness and quality of health data entered and collected in Finland is impressive.

Three aspects of the process are noteworthy: These notable elements are the early start made by Finland, the general overcoming of resistance to change, and the system's timeliness and responsiveness. Finland's capacity to move forward over time and to make progress, based on agreed approaches and standards (even prior to the widespread introduction of IT), has been important. Finland's ability for example, to overcome resistance from physicians as a result of thorough education means that the country is one step ahead of several other countries. The general timeliness and responsiveness of the system is to be admired.

The comprehensive number of components to the digital system: Finland has a wide diversity of components in terms of its eHealth support for its health and social system. Almost all records are "electronic from birth". Today, the country has direct access to a source of either valuable information or resources, particularly when taking into account the long history of registers and secondary use of data from routine health care. This means that it is sitting on a metaphorical "gold mine".

10.2 WEAKNESSES

The workshop identified a few weaknesses with respect to:

Return-on-investment and on benefits analysis: The experts had expected to hear more about how Finland justifies its investment and expenditure on eHealth, and explanation of how the country measures the benefits of its system and ensures maximum adoption by clinicians and citizens.¹² They also underlined that the clinical impact of KanTa should be assessed and monitored.

The context of care: Appeals were made to concentrate on the context of care itself, on the services such as new care pathways, chronic disease management, patient empowerment which will contribute to the necessary modernisation of the health care system.

The proactive role of healthcare practitioners (clinical champions): Particular concern was expressed with regard to getting healthcare practitioners who should act as coaches and guides to support health care improvement, working with "communities of patients" or "communities of providers".

The policy behind the tools: It was said to be absolutely important to focus on what the health system overall is attempting to achieve, and on what the crucial policy and political decisions are that underpin any of the choices of IT-based health systems and technologies. The focus should be on the health care process.

¹² This may be due either to this not forming a sufficient part of the Finnish system in its own right or it simply featuring less as an aspect of the workshop than had been anticipated.

10.3 OPPORTUNITIES - FOR FINLAND AND THE FINNISH HEALTH AND CARE SYSTEMS

Three sets of opportunities were outlined by the expert peer reviewers. They relate to the possibilities evident for Finland as a country and its health and social care system as well as for the EHTEL organisation and EHTELconnect package.

10.3.1 Policy, governance, and organisation

Find the disruptive innovation element of the health process: The views of former Finnish prime minister, Mr Esko Aho, were quoted (back) to the Finns with regard to examining the possibilities to effect positive disruptive innovation in the Finnish health/social care system. In this regard, Mr Aho had spoken publicly at a responsible research and innovation conference which took place in Dublin, Ireland on 25/26 February 2013 at which one of the eHealth experts had been present.¹³

Focus on the creativity of the actors involved, and the incentives that the actors require to act: Appeals were made to work with the creativity of the decentralised, local actors/stakeholders; and to create appropriate incentives for each of the three major stakeholders (policy-makers, physicians, and patients). Examples of the various incentives that could be considered are offered briefly in footnote but also in more detail in Annex 3 of this report.¹⁴

Build on the various components of the system: It was thought that all the various components in the system(s) mean that **Finland is ''sitting on a gold mine!''**

10.3.2 Leadership, business and benefits

Consider Finland's leadership position with regard to the transformation of health and care systems: Finland needs to examine various "grand design" issues, using systems that slice through different organisational silos.

Document the clinical effects of changes to the system: The documenting of all the clinical effects will be really useful. In terms of access to resources, Finland needs to document the health outcomes achieved e.g. for the sickest patients and those in most need of treatment.

Measure the quality of health outcomes: Several peer reviewers mentioned the value to concentrate on the quality of the health outcomes resulting from the Finnish health system, and especially in different regions and localities.

Adapt quantitative indicators: Consider the use of data indicators to e.g., register all adverse events occurring in the system, and use them to pinpoint successful decreases in negative occurrences.

¹³ See European Intersectoral Summit on Research and Innovation (EISRI). 25/26 February 2013. Trinity College, Dublin, Ireland. <u>http://eisri2013.wordpress.com</u> Accessed 27 March 2013.

¹⁴ Listed here are possible incentives for three stakeholder groups.

Patients: Empower patients through provision them with 24/7 access to results and information about treatment(s).

Physicians: Enable benchmarks that ensure that physicians can work in and with an eHealth system can enable them to focus on the *real* patients who need *real* treatment.

Policy-makers, leadership or management: Offer solutions to the next steps to putting in place a healthcare system that not only brings citizens better healthcare but in which it is also possible to see clear improvements in designated targets every three, five or seven years.

10.3.3 Opportunities for EHTEL and/or for Finland and EHTEL working together

It was thought that Finland could showcase more widely its eHealth solutions to other countries in Europe, and that – together or in parallel – EHTEL could help to build and expand the peer review scheme and model:

Showcase solutions: Finland could show more widely its eHealth solutions – starting e.g. with the ePrescribing services –to European Member States, industry, and EHTEL members.

Compare and contrast Finland's approach to those of other countries: Compare and contrast Finland's eHealth system and services to e.g., more federated approaches.

Expand the (EHTEL) peer review scheme and model: EHTEL could take the opportunity to build further on this type of scheme/model e.g., with cases from other countries and regions. This kind of peer review meeting was perceived as very fruitful from the perspective of all three parties present: the Ministry, the competence centre (THL), and the peer reviewer attendees.

10.4 THREATS

Aspects of data overload, privacy and security were identified by the peer reviewers as important, as too was eldentity. The reviewers also drew attention to occasional, but dramatic, unexpected or unanticipated consequences.

Pay even more attention to timeliness and responsiveness: Since demand for data is only likely to increase on the part of citizens and patients, more attention needs to be paid by the health providers to their degree of timeliness and responsiveness in terms of service provision.

Pay attention to the risk of data overload: The volume of data prevalent in the Finnish system in terms of its complexity may lead to a risk of overload of information. Such information overload, often out of context, might act as a threat to effectiveness and efficiency when eHealth services are fully implemented. In Norwegian legislation, for example, the expression "necessary and relevant" is used in the context of documentation and sharing of information.

Be aware of possible threats to the information system: The value and sensitivity of the data held inside the various Finnish health and care systems mean that they may be vulnerable to forms of hacking and intervention. Researchers such as Nassim Nicholas Taleb have spoken of the risks posed by "black swans".¹⁵ Increasingly, the term "grey swans" is used for more identifiable risks.¹⁶ Clearly, the Europe-wide trend to pay more attention to the importance of risk management, security, and patient safety should be taken in continuous consideration.

Consider alternative approaches for identification, health data, legacy systems and interoperability: A considerable set of technically-related points were made. These are described in detail in Annex 2 of this report, in a short report sent after the workshop by one of the attending peer review experts.

Consider various technological and organisational design issues: Here are some concerns that are inspired by recent European debates.

a) Generic eID: One could consider alternatives for the smart card use of healthcare professionals (e.g., Why is a specialised card needed? Are there other means to access registries?).

¹⁵ Nassim Nicholas Taleb (2008) The Black Swan. The Importance of the Highly Improbable. Penguin.

¹⁶ PriceWaterhouseCooper (PWC) <u>http://www.pwc.co.uk/governance-risk-compliance/publications/risk-practices-black-swans-turn-grey-the-transformation-of-the-risk-landscape.jhtml</u> Accessed 27 March 2013

b) **The roles of public authorities and private vendors.** Some consideration should be given to investing in the "middle layers" and developing appropriate guidelines and/or regulations for this. The possibilities of a shift towards the private sector should be kept in mind.



Figure 14: Family photo: European experts, Finnish delegation, moderator and EHTEL team

ANNEX 1: PROFILES OF THE INVITED EXPERTS

The experts are listed in alphabetic order of their employers' organisation.

	 Mats Larson has been active in healthcare since 1973 and has held managerial positions in regional and national healthcare in Sweden. He served as Hospital Manager during 10 years and has actively worked with hospital revitalisation-programmes as well as mergers. He holds degrees from the University of Stockholm, Gothenburg Business School as well as a Masters-degree in Information Management from the Erasmus University in Rotterdam. Mr Larson has been president of EHTEL – European Health Telematic Association as well as treasurer of EHMA – the European Health Management Association. From 2000–2004 he was CEO of Carelink – a public company set up to promote national eHealth solutions. Carelink received the first EU eHealth award for ground-breaking eHealth solutions in 2002. In 2004 Mr Larson joined Oracle as Senior Business Development Director for
Bilthong AB, Sweden	healthcare.
	From 2008 he has been CEO of Bilthong AB – with consultancy activi- ties in Europe and South Africa. Bilthong has also served as advisor to the government of Greece (2012) and is currently supporting the Swedish gov- ernments' participation in the World Economic Forum (2012–13). Since 2008 Mr Larson is the Chairman of the Board of the Swedish Medical Products Agency and serves on other boards in the Nordic coun- tries.
	Jacob Hofdiik is Partner in Casemix: "the Implementation Engineers" on
Jacob Hofdijk Casemix, The Netherlands	 systems to measure health care based on sound and healthy information. He holds a degree as a Master in Business Economics at the Rijks Universiteit Groningen (1969–1973) In May 1974 he started his career in health care at the University Hospital Leiden with the development of the BAZIS Integrated Hospital Information System. Hofdijk has been president of EFMI, the European Federation of Medical Informatics, and secretary at the Patient Classification Systems International Association. Since 1979 he has been involved in measuring health to help support clinical care processes, from both the perspective of process, quality, outcome, and cost. From 2009-2012 he elaborated together with the stakeholders the Integrated Care (INCA) model to introduce the multidisciplinary approach to the delivery of individualised care based on care standards. Hofdijk is leading the "Village of the Future" concept, which focuses on the integration of social and health care. The leading principle is to link IT with empathy, by the introduction of a Blue Line defining technological,

semantic and systems interoperability, the expectation of the citizens and

patients, and the incentive framework to support this change.



Marc Lange EHTEL, Belgium

Marc Lange: has a Master in Law, option business and European Law. He is Secretary General of EHTEL (European Health Telematic Association) since 2005.

EHTEL is a European think-tank on eHealth in Europe, which gathers representatives of all those stakeholders, from everywhere in Europe, who are committed to deploy eHealth and Telemedicine services in the field. Thanks to his position in EHTEL, Marc Lange has a global understanding of the state of affairs in eHealth in Europe and beyond.

He has been involved in European ICT projects for the public sector (i.e. social security, customs and indirect taxation, legal identity, health systems) since 1992 and has therefore a long experience in supporting EU Member States and the European Commission in coordinating the deployment of their national projects and in facilitating expert sharing of experience and good practices in a multi-disciplinary environment.



Dr Stephan Schug EHTEL, Belgium

Dr Stephan H Schug MD MPH, acts as Chief Medical Officer of EHTEL and has a long track record in European eHealth and telemedicine with a focus on interoperability and clinical services. Since 1999, he supports the strategic development of EHTEL as a multi-stakeholder platform, e.g. through working group support and event management. As Editor-in-Chief he is also responsible for the content of newsletters, briefing papers and the association's websites. He is or has been involved into European projects with a strategic dimension for eHealth interoperability like CALLIOPE, the eHealth Governance initiative (eHGI), SUSTAINS and Antilope as well as for telemedicine like RENEWING HeALTH, United4Health and the MO-MENTUM telemedicine network. With IQmed in Frankfurt/Main, Stephan provides policy and project support with an EU dimension to eHealth actors in Germany, e.g. for the eHealth platform of North-Rhine Westphalia and the ZTG GmbH. As Managing Director of DGG e.V. - Forum for eHealth and AAL - he is involved in educational activities like TELEMED and professional qualification in eHealth.



Diane Whitehouse EHTEL, Belgium

Diane Whitehouse works with EHTEL on issues related to telehealth, and integrated care (around active and healthy ageing). She is a founding partner of the UK-based business partnership, The Castlegate Consultancy, which focuses on research, policy, and deployment in eHealth, eGovernment, and eInclusion.

Diane previously worked for several years in eHealth and eInclusion in the European Commission. Her prior career history involves periods spent in academe, human rights, and publishing.

She has edited a number of books on society and technology, including on eHealth. She is currently co-Vice Chair of the International Federation for Information Processing (IFIP) technical committee on ICT and society, and Chair of IFIP's working group 9.2 on social accountability of computing.



Jacqueline Surugue Centre Hospitalier Georges Renon, France

Jacqueline Surugue is the president of the hospital section of the Federation Internationale Pharmaceutique (FIP) and immediate past president of the European Association of Hospital Pharmacists (EAHP).

She got involved in IHE Europe Steering Committee and the IHE Pharmacy Group in 2007 and, from 2009, was elected and presently re-elected for a second mandate as co-Chair for Users for both the Group and the Committee.

She is a lecturer in Pharmacy at the University of Angers and an elected member at the French National Order for Pharmacists. She currently is Chief of the Pharmacy Department of Centre Hospitalier Georges Renon, a 1,200-bed hospital in the city of Niort (Deux Sèvres).

In December 2008, she was awarded by the American Society of Health systems Pharmacists the esteemed Donald E. Francke Medal for her merits on an international level, and in June 2009, received the distinction of "Chevalier de la Légion d'Honneur" in France.



Luc Nicolas Federal Public Service for Public Health, Belgium

Luc Nicolas is a political sciences and economics graduate.

He has studied several years of Mandarin in the People's Republic of China before working during sixteen years for the medical humanitarian organization "Doctors Without Borders - Médecins Sans Frontières" both in the field and at its headquarters as Operations Regional Coordinator.

He is now expert for the Health Care Administration of the Federal Belgian Ministry of Social Affairs and Public Health in charge of the development of the Health Care Informatics and Telematics in the country, and is member of various national and international working-groups for the promotion and the coordination of Information Technology implementation in Public Health sector. He is in the Health Care Informatics, Telematics & Communication Unit.



Tom Christensen Helsedir, Norway

Tom Christensen: Born 1955. Married, 4 grown up children. MD 1981. Specialist in General Medicine 1989. PhD 2009. Primary and hospital care 1981–2000, different e-health projects, Norwegian centre of electronic patient records NTNU 2000-9. Project leader of ELIN (Electronic communication in Primary Care) 2002–07.

Medical responsible of the Norwegian e-Prescription project 2007–2009. Managing director at KITH 2009-2012, Head of department of standardization, Norwegian Directory of Health 2012–2013.

Special interest in standardised and accurate medical documentation in EMRs including coding and terminologies, quality standards and reporting to health registers. Process and decision support.

Jan-Eric Slot is the Chief Executive Officer at IHTSDO.



Jan-Eric Slot IHTSDO, Denmark

The vision of IHTSDO is to acquire, own and administer the rights to SNOMED CT and other health terminologies and/or related standards, and other relevant assets (collectively, the "Terminology Products") and to develop, maintain, promote and enable the uptake and correct use of its Terminology Products in health systems, services and products around the world and to undertake any or all activities incidental and conducive to achieving the purpose of the Association for the benefit of the Members.

Jan-Eric Slot has served previously as the CIO at the Academic Medical Centre at the University of Amsterdam, where he still lectures in IT Governance and is an editor of the HITE (Hospital Information Technology Europe) publication. Before joining the university Jan-Eric held a variety of senior positions in health related IT companies in Europe and the US. He attended medical school in Amsterdam and also holds Masters degrees in Information Systems and Business Administration and is fluent in several European languages.



Prof. Ehud Kokia immediate past Director General of the Hadassah Medical Organization

Prof. Ehud Kokia, MD, MHA is the immediate past Director General of the Hadassah Medical Organization. Prior to his appointment at Hadassah, Prof. Kokia was the CEO of Maccabi Healthcare Services. Prof. Kokia spent 17 years at Maccabi, beginning at the district level and having served in several key positions within the organization.

Prof. Kokia received his MD degree in 1974 from the Sackler School of Medicine, Tel Aviv University. Following a rotating internship at Sheba Medical Center at Tel Hashomer, Prof. Kokia served as a physician in the Israel Defense Forces. Upon completing his army service Prof. Kokia did his residency in the Department of OB-GYN at Sheba Medical Center. He then returned to active military duty as a Commander in the Israeli Air Force. Prof. Kokia is a graduate of the US Naval Flight Surgeon Course at the Naval Aeromedical Institution (NAMI) in Pensacola, Florida where he also worked on the Off Vertical Rotation Chair research project.

Prof. Kokia was a research fellowship at the University of Maryland at Baltimore's Department of OB & GYN in the Division of Reproductive Endocrinology. In 2001 he earned his Masters' degree in Health Administration from Ben Gurion University of the Negev.

Prof. Kokia has authored more than 75 scientific publications.



Madis Tiik Hekardi, Estonia

Madis Tiik is a Medical Doctor. He completed his studies at Tartu University with specialisation in family medicine in 1999.

In 2003 he earned a diploma in Public Health at the Nordic School of Public Health.

From 2001-2003 he studied IT management in Estonian Business School.

In December 2012 he successfully defended his PhD thesis "Access rights and organizational management in implementation of Estonian Electronic Health Record system" in the Tallinn University of Technology.

Since 1998 Madis Tiik has been working as family doctor. He was the chairman of The Estonian Society of Family doctors from 2001-2008. Madis Tiik is also the author of several papers, articles and lectures and has delivered keynotes in several international e-health conferences.

He was also one of the key persons developing new public service - the Call-centre 1220 - Family Doctor's advice line which is a round-the-clock service of family doctors and nurses providing medical advice to citizens (2004).

He has been involved in eHealth development projects in Estonia from the beginning in 2005 and since 2007-2011 he was a Member of the Management Board of Estonian eHealth Foundation where he has formed a strong team of professionals around him. As medical doctor with strong knowledge in IT he provides professional expertise to ensure the Estonian Electronic Health Record services serve the best interests of medical staff and patients. In recent years he has also counselled several foreign e-health related institutions and has actively contributed to the Estonian eHealth Foundation's work as the national e-health competence centre.

In September 2012 he started work as a senior adviser to Finnish the innovation fund, advising on eHealth integration and self-care service development projects.



Eddie Turnbull NHS Scotland, United Kingdom

Georg Heidenreich

Siemens, Germany

Eddie Turnbull is currently Director for eHealth, NHS, Scotland. He was previously the Head of eHealth Technical Strategy for The Scottish Government. Eddie has worked for The Scottish Government for over 30 years, either in a direct ICT leadership role or in a corporate /customer services management capacity. Over these years he has directed a number of large national programmes with ICT as the major enabler.

His current role is to ensure that eHealth activity across NHS Scotland is coordinated and supports the delivery of healthcare, and the change and improvement agendas set out by the Scottish Government.

With colleagues from Health Boards, Local Authorities, and the Scottish Government, he is contributing to the development of a strategy, and a set of underlying principles, that will enable better interoperability and joinedup working between healthcare partners.

The overarching aim is to support Health and Social care integration policy and the four pillars of Scotland's public sector reform agenda. He is actively involved is a number of Scotland's wider strategic digital initiatives, and is a member of the British Computer Society.

Since 2005 **Georg Heidenreich** is the Health care IT Standards expert in Siemens Healthcare Standards & Technology department. In that position Georg is also national delegate towards IEC 62A, HL7 Germany board member, vice-chair of the COCIR Healthcare IT committee, chair of IHE (Integrating the Healthcare Enterprise) Germany Association, and chair of the national Medical Informatics – Interoperability standards team at DIN, Berlin.

As a Software Engineer and Software Process expert Georg participated in various Medical Device development projects in Siemens Healthcare. At Erlangen-University Georg lectured on Software Design as well as Software Architecture.

A computer scientist by training, Georg started his career in consulting industries in designing and implementing software development workstations. After finishing a research cooperation between Develop-Group mbH and the Erlangen-Nuremberg university, Georg received a doctoral degree in engineering.

ANNEX 2: REPORT BY GEORG HEIDENREICH (28 FEBRUARY 2013)

The approach of STM and THL towards establishing Finland's eHealth system in many aspects already implements best practice, and little has to be added.

Despite some user complaints about specific aspects of technology, there is considerable public support for ICT solutions for health care in Finland. The standardisation mandate for THL – assigning a responsibility for development and deployment of interoperability standards – seems to be a cornerstone for the notable success of eHealth applications. For some aspects more legislation may be required to support the huge efforts that have been taken by STM, THL, KELA and other players.

In that situation, the following remarks just focus on a few selected observations regarding technology.

Question 1 "How openly can de-identified health data be managed"?

There are many advantages in having healthcare-related data available on more or less "open" platforms, and de-identification is an important measure to protect privacy of the individual data subjects ("patients").

One important note has to be made: A third party's "innocent" data i.e. for scheduling or logging may be joined together with de-identified health data resulting in a patient ID disclosure. As an example, a Radiology-Information System ("RIS") work-list has a patient name and a timestamp which can be used to map timestamps in patient images (such that via the timestamp the patient name can be retrieved from the RIS work list so that the whole record would be re-identified). Similar "joins" are possible through log files, doctor's visit logs etc. As a result de-identified data can only be "opened" after a very careful analysis of reidentification loopholes using links to other databases.

Question 2 "How to handle patient-entered non-validated health data in an EHR system?"

In critical care situations any hint on health findings may help medical professionals in diagnosis and treatment. And there are more reasons why patients may wish to enter their own findings into their EHRs.

Any record with such "informal" health information shall have a field for professional authentication purposes, while an empty "authentication" field would have the record be interpreted as "non-validated" data – be it from a patient or other source without medical confirmation. Professionals would continue entering data and authenticating these new records. Patiententered data would not have such an authentication entry, but can be authenticated after medical validation by some later authentication. Electronic signatures in a general sense are a typical technical basis for such authentication fields.

Question 3 "How to migrate data from legacy systems?"

Without a detailed look at specific (internal) data schemata of legacy systems it would take too many assumptions to explain a particular approach.

In general, from a health care quality point of view, it seems quite risky to abandon any existing patient-specific health data. Any patient data available electronically may be useful for some future health care.

In the case when the extraction of appropriate data sets from the legacy systems is not easy and if such system operations can be continued for the time being, one interoperability option would be to operate an additional national lightweight-index server with entries just listing visit metadata (like e.g. the time, organization and patient-ID) that then can be used to narrow down specific access to the real health care "payload" data in the respective local legacy database records. Any healthcare professional could easily browse that index and focus on whatever (s)he considers important for the current patient encounter. Note that the metadata in the index would be more valuable with clinical information (such as an ICD-code) in it, but on the other hand would require more privacy protection measures.

If operating the legacy system is not possible anymore, the extraction of health data is required on a per patient basis, for a full migration supporting the original data format as far as possible. Based on standardised XML/HL7, "wrapping" structures may be used as the context of such extracted data, which is then represented in nested XML/HL7 elements, if necessary via base64-encoded strings. For consistency reasons, it is not recommended to continue entering original data into the old format system after such a migration. The same metadata recommended for the above index server would be useful (for search and retrieval) as explicit mark-up in such structured XML/HL7containers. Preserving the original data lowers the risk of errors and losses during migrating the medical patient data while the structured wrapper provides flexibility for use in various (future) IT-systems.

Question 4 "What can be done to improve interoperability of health care IT systems?"

The current situation – with political support and an existing standardisation mandate for THL – is extremely favourable. However, large data assets exist in legacy databases and regional/local system vendors are trying to maintain their business cases.

Legacy system integrators as well as future system's designers need good guidance on how to develop interfaces that meet the purpose of the interface standards, as intended by THL. Some typical practices from IHE for that purpose are:

- a) Stakeholder participation when drafting technical (standard) specifications. (The presentations indicate that this is already being practiced by THL.)
- Easy availability of specifications to vendors. (Presentations by THL indicate "free" use already.)
- c) Definition of use-cases at the health care level, in order to explain the intention of some technical system to the potential users together with prosaic interface information model guidelines (written in natural language) as the basis for communicating the rules for interoperability to implementers. In order to achieve something like "semantic" interoperability, it is not enough to explain interfaces at the technical level instead the use and intention of messages and records as wells as identifiers for documents, records and subjects must be explained with respect to the use-cases and at the application (i.e. the health care) level.
- d) Conformance testing events to give feedback to the vendors and confidence to the users of IT solutions. For that purpose, the THL-published specifications should have acceptance criteria for interface conformity with them and vendors shall be invited to test their implementations in a transparent way during national "plugfest" (or "Connect-a-thon") events.

Summary (G. Heidenreich)

The presentations by THL and the Health Ministry showed one of the most advanced national eHealth systems worldwide, both in terms of functionality as well as coverage and usage. The clear governance for policies, standards and other technology foundations seems to be one reason for that success. However the responsible and strategic handling of health care data in regional/local legacy systems very much depends on more political support and maybe expanded legislation.

ANNEX 3: REPORT BY EHUD KOKIA, ISRAEL (11 MARCH 2013)

I would like to start by thanking you and the organizing committee for inviting me to this important and interesting workshop. I hope that I was able to contribute to this workshop.

As for the remarks regarding the development of [eHealth] in Finland:

We must all remember that health IT is only a major and important tool that enable the leaders to accomplish their strategy and policy, but it is not a replacement for a sound policy and strategy.

The system in Finland is an established system that is working for many years. It is far beyond the implementation stage regarding the physicians. However, because the system was buil[t] "bottom up" there are various software and various vendors, so there is a lack of uniformity.

It is important to mention that the Finnish citizens are satisfied from the health system.

Another big advantage is the close relationships between the health system and the social care system. This is something that is not common in many places.

The fact that the responsibility for the health system is on the municipalities is, as I see it, a disadvantage because it is very hard to become professional when you have to deal with 6,000 citizens.

The Finnish health system is right now in the "data" stage, and [the] big advantage is to make the big leap to the "knowledge" stage.

I can recognise three main stakeholders in the Finnish health market: the patients, the health care professionals (mainly the physicians), and the [organisations] (mainly the government).

In order to upgrade the system there should be an added value for every one of the three parties.

The patients: Empowerment regarding knowledge on the system and the services, better services: The option to make electronic visits to physicians, the option to receive your blood test on the same day on your computer, to get information about your drugs purchase, about physicians' visits and the ability to handle your personal health record.

The physicians: Tools that will enable them to give better treatment, tools to focus on the really sick patients, to make the system more user friendly, and to be able to receive benchmarking regarding performance.

The [organisation/government]: The ability to lead and direct the future directions of the health system, to measure the effectiveness of the system. To build performance indicators in the clinical quality world, the perceived quality (satisfaction), and the economic indicators, the ability to bridge the gap in the world of inequality. To build registries.

We must give a lot of thinking to [mHealth], taking into account the fact that Finland is a leading country regarding smart phones.

In summary: Finland is standing at a very good starting point and should step up for the next major improvement.



Country Brief: England

Authors: D. Whitehouse, S. Giest, J. Dumortier, J. Artmann, J.Heywood

October 2010





European Commission, DG Information Society and Media, ICT for Health Unit





About the eHealth Strategies study

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

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For England, Diane Whitehouse provided initial information on policy contexts and situations, policies and initiatives and examples for specific applications which has been further rigorously reviewed. Diane Whitehouse is a former European Commission project officer, and is currently a partner in a United Kingdom-based policy partnership.

Reviewer

Roderick Tooher

Contact

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

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Executive summary

England has a long history with eHealth. The National Programme for IT in England had already begun in 2002 and acted as the basis for eHealth deployments. In conjunction with this the 2002 policy paper "Delivering 21st century IT support for the NHS: national strategic programme"¹ was created. Not that this was the first policy paper to focus on technology in healthcare: as far back as 1998, specific policy was developed for this field.

The current situation of the English eHealth strategy is under review due to changes in government. The newly elected Coalition Government is expected to indicate a new direction for the main IT programmes and develop a new Information Strategy towards the end of 2010 which will be subject to a public consultation exercise before finalisation.

In order to consider the progress that has been made so far in England towards reaching eHealth interoperability objectives the following eHealth applications have been examined: patient summaries, electronic health records, ePrescription, standards, and telemedicine. In England the situation is as follows:

A patient summary programme known as the Summary Care Record Programme has been nationally implemented in England since 2008. However, some form of electronic patient record has existed since the mid eighties due to the high level of computer use in General Practitioners' (GPs) practices from this time onwards.

In terms of ePrescription England has two programmes for electronic prescribing in existence. One, Electronic Prescription Service (EPS) is directed at the primary care sector, GPs and clinics, and synchronises all steps from the generation to the despatch of the prescription. The other, ePrescribing, is aimed at institutions such as hospitals and includes a decision support component. In 2009 the Department of Health confirmed that over 500,000 prescriptions had been transmitted electronically in England. It is also known that some institutions have been using some form of electronic prescribing for over ten years.

On standards, England is included in the United Kingdom and its membership of the IHTSDO (International Health Terminology Standardisation Organisation). Alongside this, a Health Informatics Service Benchmarking and Accreditation Scheme was launched in 2008² to help health informatics providers and Information Management &Technology departments.

Telemedicine initiatives in England are not combined under a single national programme but rather run at the local authority level. The Department of Health is currently funding three demonstrator projects, at local authority level, that aim to develop an evidence base for the use of telecare and telehealth in England. Aside from this, NHS direct, which provides health advice and reassurance on the phone as well as through an online library of medical advice, could also be considered as a form of telemedicine application.

Following the election of a new UK Coalition Government in May 2010 there have been clear indications of a change of direction for England's eHealth Strategy. The new Government has set out

¹ Department of Health 2002

² NHS Connecting for Health 2010



England

a major reform programme to radically alter the structure and processes of the National Health Service. This programme aims to have a health service more focussed on the successful patient outcomes from its services, an emphasis on taking decisions with patients and a significant reduction in bureaucracy.

On eHealth services the new Government has made significant announcements on:

- A review of the National Programme for it (see page 19)
- A review on the Summary Care Record (see page 21)
- A consultation exercise for a new information strategy.

A new Information Strategy will be one of the underpinning actions for the reform programme. To this end the Government has launched a consultation exercise under the title "Liberating the NHS: An Information Revolution".

Key proposals for the Information Revolution include:

- people having greater access to and control of their health and social care records
- more information on treatments, conditions and lifestyle choices, helping people look after their own and their family's health and care
- greater emphasis on information generated by patients and service users (for example, patient-reported outcomes measure (PROMs), experience data, and feedback)
- a wider range of providers to analyse and present information to the public
- improved use of digital technologies.

The results from this consultation are expected to be known in 2011.



England

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1 Introduction to the report

1.1 Motivation of the eHealth Strategies study

Following the *Communication* of the European Commission (EC) "eHealth – making healthcare better for European citizens: An action plan for a European eHealth Area" ³ all Member States of the European Union (EU) have generally committed themselves to develop and issue national roadmaps – national strategies and plans for the deployment of eHealth applications addressing policy actions identified in the European eHealth Action Plan. It should be underlined that the National Programme for IT in England is the basis for eHealth deployments which started in 2002, two years before the eHealth Action Plan was published.

The 2004 eHealth Action Plan required the Commission to regularly monitor the state of the art in deployment of eHealth, the progress made in agreeing on and updating national eHealth Roadmaps, and to facilitate the exchange of good practices. Furthermore, in December 2006, the EU Competitiveness Council agreed to launch the *Lead Market Initiative*⁴ as a new policy approach aiming at the creation of markets with high economic and social value, in which European companies could develop a globally leading role. Following this impetus, the Roadmap for implementation of the "eHealth Task Force Lead Market Initiative" also identified better coordination and exchange of good practices in eHealth as a way to reduce market fragmentation and lack of interoperability⁵.

On the more specific aspects of electronic health record (EHR) systems, the recent *EC Recommendation on cross-border interoperability of electronic health record systems*⁶ notes under "Monitoring and Evaluation", that "in order to ensure monitoring and evaluation of cross-border interoperability of electronic health record systems, Member States should: consider the possibilities for setting up a monitoring observatory for interoperability of electronic health record systems in the Community to monitor, benchmark and assess progress on technical and semantic interoperability for successful implementation of electronic health record systems." This study is a contribution to monitoring the progress made in establishing national/regional EHR systems in Member States. It also provides analytical information and support for current efforts made by the European Large Scale Pilot (LSP) on cross-border Patient Summary and ePrescription services the epSOS- European patients Smart Open Services-⁷, and its accompanying thematic network, CALLIOPE⁸. England has contributed substantially to the work of both these pan-European initiatives.

Earlier, in line with the requirement to "regularly monitor the state of the art in deployment of eHealth", the Commission already funded a first project to map national eHealth strategies – the eHealth ERA: "Towards the establishment of a European eHealth

³ European Commission 2004

⁴ European Commission 2007

⁵ European Communities 2007

⁶ European Commission 2008

⁷ European Patients Smart and Open Services (epSOS)

⁸ Calliope Network

Research Area" (FP6 Coordination Action)⁹ -and a project on "Good eHealth: Study on the exchange of good practices in eHealth"¹⁰ mapping good practices in Europe - both of which provided valuable input to the present *eHealth Strategies* work and its reports. Member States' representatives and eHealth stakeholders for example in the context of the *i2010 Subgroup on eHealth* and the annual European High Level eHealth Conferences have underlined the importance of this work and the need to keep it updated to continue to benefit from it.

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

1.2 Survey methodology

National level information has been collected through a Europe-wide network of national correspondents which was enhanced by materials provided directly by the health authorities concerned.

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

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

Under each section, specific questions were formulated and combined with free text fields and drop-down menus. The drop-down menus were designed to capture dates and stages of development (planning/implementation/routine operation). In addition, dropdown menus were designed to limit the number of possible answering options, for example with regard to specific telemedicine services or issues included in a strategy document. The overall purpose was to assure as much consistency as reasonably possible when comparing developments in different countries, in spite of the well-known disparity of European national and regional health system structures and services.

Under Section B on eHealth implementation questions regarding the following applications were formulated: existence and deployment of patient and healthcare provider identifiers, eCards, Patient Summary, ePrescription, Standards as well as Telemonitoring and Telecare.

The data and information gathering followed a multi-stage approach. In order to create a *baseline* for the progress assessment, the empirica team filled in those parts of the

⁹ empirica, STAKES et al. 2007

¹⁰ European Commission; Information Society and Media Directorate-General 2009



respective questions dealing with the state of affairs about 3 to 4 years ago, thereby drawing on data from earlier eHealth ERA reports, case studies, etc. to the extent meaningfully possible. In the next step, national correspondents, and respectively partners from the study team, filled in the template on recent developments in the healthcare sector of the corresponding country. These results were checked, further improved and validated by independent experts whenever possible.

Progress of eHealth in England is described in chapter 3 of this report, in the respective thematic subsections.

This report was subjected to both an internal and an external quality review process. Nevertheless, the document may not fully reflect the current situation. The analysis may not be exhaustive due to focusing on European policy priorities as well as due to limited study resources, and the consequent need for preferentially describing certain activities over others. Also, the views of those who helped to collect, interpret and validate contents may have had an impact. Particularly in the case of England and the United Kingdom, since May 2010, a number of potentially large-scale changes are anticipated in the health system that it has not been possible to reflect fully in this report.

1.3 Outline

The report provides general information on the English healthcare system, as well as on specific issues of the eHealth structure and the ongoing development. It is structured as follows:

Chapter 2 is concerned with the overall system setting, such as decision making bodies, healthcare service providers and health indicators data

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

Chapter 4 provides a brief summary of the current situation.

2 Healthcare system setting

Key figures about healthcare in the United Kingdom¹¹:

Total population: 61,411.69 (OECD 2008);

Life expectancy at birth: 79.9 years (OECD 2007);

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

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

2.1 Healthcare governance

Following elections in the UK in May 2010, the set-up of the National Health Service (NHS) is under an important review. The policy changes at hand will impact on the eHealth policy in NHS England. These changes are taken into account in this report to the extent that they are already discernible today in October 2010. However, much of this report focuses on the organisational conditions that prevailed in the NHS at the time that the first draft of this report was finalised (in early May, 2010).

We outline here, however, some developments since May 2010. The following information on healthcare governance should be seen in the light of government documents published on 12 July 2010, notably a White Paper entitled "Equity and Excellence: Liberating the NHS". A declared objective of this policy document is to make the NHS more efficient and productive so as to ensure that it can cope with increasing demands on its services.

The White Paper sets out four key points:

- putting patients first through giving them more information and greater choice and control over their care – 'no decision about me without me'
- improving healthcare outcomes by ensuring that professionals are free to focus on improving health outcomes so that these are among the best in the world. Improving the quality of care will become the main purpose of the NHS
- autonomy and accountability involving giving power back to NHS professionals and healthcare providers, giving them more autonomy and, in return, making them more accountable to patients and the public
- cutting bureaucracy and improving efficiency by continuing to reinvest savings of up to £20 billion in front-line services by 2014 in line with the Quality, Innovation, Productivity and Prevention agenda.

Regarding the first point, it is intended to give patients more choice and control through the modernisation of IT ("an information revolution"). Patients will be able to rate the quality of the care they receive. "Healthwatch", a separate organisation, will ensure "that patients are involved in decisions about their care and that their views are considered when commissioning services".

¹¹ These figures relate to the United Kingdom as a whole rather than to England specifically.

When it comes to improving healthcare outcomes (the second point), the White Paper announces a move away from "top-down targets" towards health outcomes targets. "A new outcomes framework will be introduced based on effectiveness of treatment; safety of treatment and care; and broader patient experience of care. " This framework will use quality standards developed by the National Institute for Health and Clinical Excellence. In addition, commissioning care, payment systems, and inspection processes will all be built on the outcomes framework.

In the field of decision-making (autonomy and accountability), more freedom is given to healthcare professionals and service providers "to shape services around the needs and choices of patients." The Strategic Health Authorities which currently oversee commissioning will be phased out by 2012/13, to be replaced with a new independent NHS Commissioning Board. In addition to this development, the White Paper mentions the following changes in the governance of the NHS:

• All NHS trusts will become foundation trusts and have more freedom. Any provider that can meet safety and quality standards will be able to provide NHS services. This greater freedom will also apply to the way in which local community health services are delivered.

• Monitor will be developed into an economic regulator and the Care Quality Commission will act as a quality inspectorate across health and social care.

• Monitor and the Care Quality Commission will act as regulators. Providers will need a licence to ensure that safety, quality and the continuity of essential services are maintained.

• Primary Care Trusts and practice-based commissioning will be replaced by General Practitioner (GP) Consortia, which will work with other health and care providers, in partnership with local authorities and local communities, to commission the majority of NHS services for their patients. The role of the Secretary of State in the NHS will span five key areas:

i. setting a formal mandate for the NHS Commissioning Board;

ii. holding the NHS Commissioning Board to account on delivering improvements in choice and patient involvement, and in maintaining financial control;

iii. arbitration, where disputes arise between NHS commissioners and local authorities;

iv. responsibility for Department of State functions including setting the overall NHS policy and legislative frameworks, and determining the comprehensive service which the NHS provides;

v. accounting annually to Parliament for the overall performance of the NHS, public health and social care systems.

• Local authorities will have new functions that join up with the commissioning of local NHS services, social care and health improvement. This will provide efficiencies and build partnerships to drive service change and priorities.

Finally, with regard to the objective of "Cutting bureaucracy and improving efficiency", the White Paper announces a reduction in management costs and in any duplication in the system. "There will also be reductions to budgets for centrally managed programmes,



such as consultancy services and advertising spend. NHS services will increasingly be empowered to be the customers of a more plural system of IT and other suppliers."

Some of these changes will require primary legislation, and a Health Bill will be produced in autumn 2010.

The figure below presents an outline of the new processes envisaged within the NHS in England:



Decision making bodies, responsibilities, sharing of power

In England, ten Strategic Health Authorities (SHAs) are responsible for healthcare in their region. This includes the development of strategies for health services in their local areas, ensuring quality and the appropriate capacity for different services. SHAs are accountable to the Secretary of State for Health, who is the government minister responsible for the NHS in England and answerable to Parliament for its work. The new Coalition Government has indicated its intention to abolish SHAs. A new national Commissioning Body is proposed which may absorb many of the functions of SHAs.

Healthcare service providers¹²

There are 152 Primary Care Trusts (PCTs) in England which are responsible for the commissioning of health services for their local population, and for the provision of a variety of primary healthcare services. PCTs handle approximately 80% of the total NHS budget, managing budgets for local services. PCTs are performance managed by the SHAs. The new Coalition Government has indicated its intention to abolish PCTs. Their proposed replacements will be known as GP Consortia.

NHS secondary care services are run and managed by NHS Trusts. There are three main types of trusts:

- [1] Acute trusts, providing medical and surgical care and are usually centred on a teaching or district general hospital; an acute trust may manage more than one hospital.
- [2] Mental health trusts, either providing services in hospitals or in the community.

¹² Department for Work and Pensions 2008

[3] Ambulance trusts.

Some NHS Trusts are performance managed by the SHAs and accountable to the Secretary of State. Since April 2004, certain NHS trusts (the best performing hospitals) have been allowed to receive foundation status. These hospitals have greater freedoms to manage their own affairs and are accountable to the local community through a stakeholder board of Governors, rather than to the Secretary of State. Monitor is an independent body responsible for authorising, monitoring and regulating foundation trusts. Foundation Trusts represent the Government's commitment to decentralising the control of public services and are viewed as a way to improve service responsiveness and quality of care in the NHS. Since May 2010, the new Coalition Government has indicated it wants all trusts to be transformed into Foundation status.

Figure 1	1: Important	features of	f primarv	healthcare	organisation	in England
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Political/administrative unit responsible for primary healthcare	The National Health Service provides the majority of healthcare in England, including primary care, in-patient care, long-term healthcare, ophthalmology and dentistry. The National Health Service Act 1946 came into effect on 5 July 1948. Private healthcare has continued parallel to the National Health Service, paid for largely by private insurance: it is used by about 8% of the population, generally as an add-on to NHS services. In the first decade of the 21st century the private sector started to be increasingly used by the NHS to increase capacity.
Consumer Choice	General practitioners are usually the first point of contact for nearly all National Health Service patients. They can direct a patient to other National Health Service services. A person has the right to be registered with the general practitioner surgery (i.e., office) of their choice. It is the general practitioner who advises the patient about choosing the best specialist care when it is needed. ¹³
Financing	The National Health Service is largely funded from general taxation (including a proportion from National Insurance payments). The government department in England responsible for the National Health Service is the Department of Health. Scotland, Wales and Northern Ireland have their own devolved health administrations. Most of the expenditure of the Department of Health in England (£98.7 billion in 2008/2009) is spent on the National Health Service.
Public or private providers	Many general practitioners are self-employed. They hold contracts, either on their own or as part of a partnership, with their local primary care trust. The profit made by general practitioners varies according to the services they provide for their patients and the way they choose to provide these services. Those salaried general practitioners who are employed directly by primary care trusts earn between £53,249 to £80,354 a year depending on their length of service and experience. ¹⁴
Gatekeeping function of the General Practitioner (GP)	General practitioners are usually a patient's first contact point. If a patient needs to go to hospital to see a specialist, she/he has the right to choose to which hospital the general practitioner refers him/her. This legal right was introduced in April 2009. It enables the patient to choose from any hospital offering a suitable treatment that meets National Health Service standards and costs. The patient can choose the hospital according to what factors matter most, including location, cleanliness, waiting times, reputation, clinical performance, visiting policies, parking facilities or patients' comments. ¹⁵

 ¹³ NHS Choices 2009
¹⁴ NHS Careers 2010
¹⁵ NHS Choices 2009



2.2 **Reforms and priorities of health system/public health**

The government introduced a large number of different healthcare reforms in England over the nine years until early 2010. To summarise, they focused on the following issues:¹⁶

- Substantial real terms increases in NHS expenditures (not a reform in itself, but very important, and primarily motivated by the Government's objective to bring healthcare spending in line with the EU average but also used as "investment" to enable reform);
- Commitment to markets, choice and payment-by-results as incentives for hospitals to reduce waiting times/lists and improve various indicators of quality (e.g. mortality rates);
- Emphasis on targeting more resources towards primary care services (and in particular with respect to improving services in deprived areas, as part of their effort to reduce inequalities in health outcomes across socio-economic and geographicallydefined groups), and
- Attempts to better integrate health and social care.

A central policy document, which followed up on a 10-year healthcare reform from 2000, is the "Health reform in England: update and commissioning framework"¹⁷ (2006). It outlines past achievements and future plans for healthcare in England. The new Coalition Government published a White Paper *(Equity and Excellence: Liberating the NHS)* in summer 2010 which sets out major reforms to the structure and functions of the different parts of the NHS in England.

3 eHealth Strategies survey results

The following sections present the results of the eHealth Strategies country survey in Europe. In a first section, the eHealth policy actions undertaken in Europe generally are presented briefly, in England until 2002, and again in 2010, are presented briefly. This is followed by a presentation of administrative and organisational measures taken. Section 0 presents results on key eHealth applications. Section 3.4 focuses on the technical side of eHealth, namely the role of patient and healthcare provider identifiers and the role of eCards. Legal and regulatory facilitators as well as financing and reimbursement issues are presented in the following chapters, 3.5 and 3.6. The report concludes with evaluation activities (3.7) in the country and an outlook (4).

¹⁶ Oliver 2006

¹⁷ Department of Health 2006



3.1 eHealth policy action

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

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

3.1.1 Current strategy/roadmap

Due to changes in the English NHS in the wake of elections in the United Kingdom in May 2010, the English eHealth strategy is currently under review. The summary of the policy documents which follows is therefore to be read with the appropriate caution as the direction of policy may still change. The new Coalition Government is expected to carry out a public consultation on a proposed Information Strategy and indicate a new direction for the main IT programmes during the latter part of 2010.

The White Paper: 'Equity and excellence: liberating the NHS'

In September 2010, the Minister of State, Department of Health (Mr. Simon Burns) declared:

"The National Programme for IT is being reconfigured to reflect the changes

described in the White Paper "Equity and Excellence: Liberating the NHS" and the outcome of the cross-Government review of ICT projects initiated in May.

A departmental review of the National Programme for IT has concluded that we deliver best value for taxpayers by retaining a national infrastructure and applications whilst devolving leadership of IT development to NHS organisations on the principle of connected systems and interoperability with a plural system of suppliers.

The programme has delivered a national infrastructure for the NHS, and a number of successful national applications such as choose and book, the picture archiving and communications (digital imaging) system, and the electronic prescription service should now be integrated with the running of current health services.

The remaining work of the programme largely involves local systems and services, and the Government believe these should now be driven by local NHS organisations. Localised decision making and responsibility will create fresh ways of ensuring that clinicians and patients are involved in planning and delivering front line care and driving change. This reflects the coalition Government's commitment to ending top-down government." **Delivering 21st**

NHS: national

century IT support for the

strategic

programme

It is understood that certain commitments under the National Programme will continue up until their completion in 2012. From then on, it is envisaged that most future applications will be locally driven and delivered while they remain consistent with national information standards.

Prior to the recent changes, the "Delivering 21st century IT support for the NHS: national strategic programme"¹⁸ from 2002 had been the policy paper concerned with the major developments in the deployment and use of information technology in the National Health Service (NHS). The document outlined the vision, strategy, and work streams that would connect the delivery of the NHS Plan with the capabilities of modern information technologies.

The following five documents were the policy papers that referred to eHealth strategies in England between 1998 and 2002 until the publication of the Delivering 21st century IT support for the NHS: national strategic programme.

Earlier eHealth strategies:

Information for health: an information strategy for the modern NHS (1998)

The NHS Plan: a plan for investment, a plan for reform (2000)

Building the information core implementing the NHS Plan (2001)

Securing our future health: taking a long-term view - the Wanless Report (2002)

Delivering the NHS Plan: next steps on investment, next steps on reform (2002)

Information for health: an information strategy for the modern NHS 1998-2005¹⁹ (September 1998): The purpose of this information strategy was to ensure that information is used to help patients receive the best possible care. The strategy was to enable NHS professionals to have the information they need both to provide that care and to play their part in improving the public's health. The strategy also aimed to ensure that patients, carers, and the public were to have the information necessary to make decisions about their own treatment and care, and to influence the shape of health services generally.

<u>The NHS Plan: a plan for investment, a plan for reform</u>²⁰ (July 2000): outlined the vision of a health service designed around the patient: a new delivery system for the NHS as well as changes between health and social services, changes for NHS doctors, for nurses, midwives, therapists and other NHS staff, for patients and in the relationship between the NHS and the private sector.

<u>Building the information core implementing the NHS Plan</u>²¹ (January 2001): considered the implications of The NHS Plan for the necessary information and IT infrastructure to support a patient-centred delivery of care and services. It built on and updated Information for Health, the information strategy for the NHS, and provided a clearer focus on what priorities for successful delivery should be.

¹⁸ Department of Health 2002

¹⁹ Department of Health and NHS Executive 1998

²⁰ Department of Health 2000

²¹ Department of Health 2001



<u>Securing our future health: taking a long-term view - the Wanless Report²²</u> (January 2002): assessed the long-term resource requirements of the health service in the United Kingdom. It makes several recommendations for IT in the NHS: doubling and ring-fencing IT expenditure; using stringent, centrally-approved standards; and auditing achievements.

Delivering the NHS Plan: next steps on investment, next steps on reform

<u>Delivering the NHS Plan: next steps on investment, next steps on reform²³</u> (April 2002): was a progress report on the NHS Plan up to 2002, that noted achievements and provided details of planned changes to the programme. Among other topics, it dealt with supply-side reforms and structural changes to the health service, payment by results, explicit patient choice, diversity of supply, devolution of decision-making away from the centre, and changes in job design and work organisation.

The figure below shows a timeline for the different policy documents in England.

Figure 2: English policy documents related to eHealth 1998-2002



© empirica 2009

Recent Developments

The new Coalition Government is now developing a new Information Strategy during 2010-11 which will be subject to a consultation exercise before finalisation.

²² Department of Health 2002

²³ Department of Health 2002

3.2 Administrative and organisational structure

NHS Connecting for Health delivers the National IT programme

Local NHS

Health

elements define own IT priorities

supported by

Connecting for

⁹ Since 2005, NHS Connecting for Health, which is currently within the Department of Health's Informatics Directorate, ²⁴ has been responsible for the delivery of the National Programme with the management of the IT-related functions and financed by the English Department of Health (NPfIT).

The National Programme was originally expected to operate for up to five years, but continued for a longer period, and has seen changes to its content and revisions to its delivery timetable.

In 2006, the NPfIT Local Ownership Programme was commissioned. Through this programme, the local elements of the NHS (its Strategic Health Authorities and Primary Care Trusts) were able to define their own IT priorities to improve healthcare standards and delivery. These local NHS organisations also became accountable and responsible for the delivery of the National Programme for IT. NHS Connecting for Health supports this delivery.

The maintenance of the national eHealth infrastructure is the responsibility of the two remaining Local Service Providers, British Telecom and the Computer Services Corporation.

Regarding the involvement of stakeholders, England found several solutions varying from informal consultation to temporary working groups and stakeholder representation in official decision-making bodies. These mechanisms are used to solicit and integrate the different views – this is also expressed e.g. in the "Information for health: an information strategy for the modern NHS" strategy. Here, it is stated that: "the development of policy, and the management of national IM&T projects, must be guided by the needs of the various stakeholders"²⁵. The arrangements defined include e.g. a Clinical Systems Group, and associated clinical information advisory groups, local involvement of patients and carers as well as collaboration with other public services expressed in partnership arrangements both nationally between government departments and locally between individual NHS and other organisations.

Overall, in England, considerable effort has been expended to engage with clinical and patient stakeholders so that they can appreciate the benefits as well as the challenges in implementing what are complex new information systems. Clinical Leads (or champions) bring their expertise to bear on the design of these new joined-up systems. Patient or consumer concerns can be expressed through an independent National Information Governance Board that promotes a published guarantee on the way personal data are managed within the electronic health records.

Main challenges connected to issues of organisation and finance

The main challenges for the administrative framework for eHealth in England are largely connected to organisational and financial issues: The Local Ownership Programme has devolved responsibility for implementation to Strategic Health Authorities and local Trusts. This brings with it demands for additional skills and resources to carry out these responsibilities. Furthermore, eHealth activities will not stop with the completion of the National Programme, but will continue with the upgrading and replacement of older

²⁴ NHS Connecting for Health 2010

²⁵ NHS executive 1998, p.87



systems and with the addition of new functionalities. Such continuing costs will need to be assessed²⁶.

Recent Developments

On 9 September 2010 the English Health Minister, Simon Burns, made the following announcement on the outcome of a Review of the NPfIT:

"The National Programme for IT is being reconfigured to reflect the changes described in the White Paper "Equity and Excellence: Liberating the NHS" and the outcome of the cross government review of ICT Projects initiated in May".

A Department of Health review of the National Programme for IT has concluded that we deliver best value for taxpayers by retaining a national infrastructure and applications whilst devolving leadership of IT development to NHS organisations on the principle of connected systems and interoperability with a plural system of suppliers.

The programme has delivered a national infrastructure for the NHS, and a number of successful national applications such as Choose and Book, the Picture Archiving and Communications (digital imaging) System, and the Electronic Prescription Service should now be integrated with the running of current health services.

The remaining work of the programme largely involves local systems and services, and the Government believes these should now be driven by local NHS organisations. Localised decision making and responsibility will create fresh ways of ensuring that clinicians and patients are involved in planning and delivering front line care and driving change. This reflects the coalition government's commitment to ending top-down government.

The new approach to implementation will be modular, allowing NHS organisations to introduce smaller, more manageable change, in line with their business requirements and capacity. NHS services will be the customers of a more plural IT supplier base, embodying the core assumption of connecting all systems together rather than replacing all systems.

This approach will also address the delays, particularly in the acute sector, that resulted from the National Programme's previous focus on complete system replacement. It will allow NHS Trusts to retain existing systems that meet modern standards, and move forward in a way that best fits their own circumstances.

An appropriate structure for health informatics is a key element of the organisational design work currently underway following the publication of the White Paper "Equity and Excellence: Liberating the NHS". The direction of travel being announced today for IT services very much reflects the key theme of the White Paper, of bringing decisions closer to the front line. It follows that the National Programme will no longer be run as a centralised programme. Some elements will need to continue to be nationally managed and it is expected that new structures will be fully in place by April 2012.

Existing contracts will be honoured and it is vital that their value be maximised. However, by moving IT systems closer to the frontline, it is expected to make additional

²⁶ Within the NHS in England, a distinction is made between national costs of NPfIT which are in the public domain and local cost consequences of these investments which are not collected centrally.



savings of £700 million, on top of the £600million announced by the previous administration in December 2009. These savings will mean that the total cost of the programme will be reduced significantly from the original forecast of £12.7billion for combined central and local spending to £11.4 billion."

3.3 Deployment of eHealth applications

3.3.1 Patient summary and electronic health record

In this study, the epSOS project's definition²⁷ of a patient summary was used as a general guideline. There a patient summary is defined as a minimum set of a patient's data which would provide a health professional with essential information needed in case of unexpected or unscheduled care (e.g. emergency, accident), but also in case of planned care (e.g. after a relocation, cross-organisational care path).

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

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

Summary Care Record Implementati-on started in late 2008

In England, a basic patient summary is known as the Summary Care Record²⁸ (SCR). The Summary Care Record Programme has been piloted since 2007 and national implementation started in late 2008.

As the vast majority of General Practitioners (GPs) in England have used computers since the mid-nineteen eighties, and have hence used some form of patient record, the record "is created from the records of organisations already delivering care to a patient"²⁹ such as GPs' practices. The Summary Care Record contains a core set of essential information of demographic details, medications, allergies and adverse reactions to support safe treatment in emergency care.

Data storage terms

In terms of storage, the data are saved in the Personal Spine Information Service (PSIS) database. The PSIS is one part of the NHS Care Records Service (NHS CRS). The other

²⁷ European Patients Smart and Open Services (epSOS)

²⁸ NHS Connecting for Health 2010

²⁹ NHS Connecting for Health 2009, p.5

major data component is the Personal Demographics Service (PDS) database. This database holds each patient's demographic information. The PDS was created in 2004, and it will eventually replace the four existing demographic services so as to become the sole source of patient demographic information for all NHS healthcare systems. The PSIS database and the PDS database are also components of the Spine.

The Spine is the collection of databases and applications that provide several services to NHS staff.

As well as the PDS (to maintain patient demographic details) and the PSIS (to maintain patient clinical records), the Summary Care Record Application allows healthcare staff - with appropriate access rights - to gain controlled access to patient information provided by the PDS and the PSIS. Other systems and services supported by the Spine include the Electronic Prescription Service and Choose and Book (which enables the making of appointments).

While the Summary Care Record application is a Spine application, ePrescriptions and Choose and Book are services that the Spine supports. However, they are not themselves databases or applications on the Spine.

Planned EHR, extending SCR functionality

The scope of the content of the Summary Care Record has been subject to a review which reported in October 2010. The review concluded that the core record should only contain a patient's demographic details, medications, allergies and adverse reactions. Any further information added to the Summary Care Record should require explicit consent from the patient³⁰.

Summary Care Records are viewed in urgent and emergency care settings, for example in GP Out of Hours Services, Walk in Centres and Hospital Emergency Departments. Summary Care Records can be viewed by authorised healthcare staff either through the web based Summary Care Record Application or through clinical systems which are integrated directly with Summary Care Records. Systems that are provided centrally and existing local clinical systems are being integrated with the Summary Care Record.

3.3.2 ePrescription

Two programmes: ePrescribing and the Electronic Prescription Service In the framework of this study and following work in epSOS³¹, ePrescription is understood as the process of the electronic transfer of a prescription by a healthcare provider to a pharmacy for retrieval of the drug by the patient. In this strict sense, only a few European countries can claim to have implemented a fully operational ePrescription service.

There are two programmes for electronic prescribing in the United Kingdom, ePrescribing³²,³³ and the Electronic Prescription Service³⁴ (EPS).

The latter is aimed at the primary care sector (general practitioner surgeries and clinics). EPS involves the generation, transmission, receiving and despatching of the prescription for payment. The implementation of release 1 of the EPS started in February 2005 and is

³⁰ NHS Connecting for Health 2010

³¹ European Patients Smart and Open Services (epSOS)

³² NHS Connecting for Health 2010

³³ There are certain exclusions under ePrescribing in England which refer to controlled drugs.

³⁴ NHS Connecting for Health 2010

almost complete³⁵. The implementation of release 2 began in 2008 and includes electronic signatures and the transmission of the prescription automatically to a pharmacy nominated by the patient³⁶.

NHS Connecting for Health issued organisational and technical guidelines to support the implementation of EPS software at the primary care and community pharmacy level.

In terms of an estimated ePrescription share, the Department of Health stated in September 2009 that "In terms of services currently routinely being used by clinicians and patients, on any typical day in the NHS the national programme already enables: Over 500,000 prescriptions to be transmitted electronically (33% of average total daily prescriptions), reducing errors and inefficiencies"³⁷.

Most, if not all, of the EPS Release 2 systems for GPs 'practitioners' surgeries have been accredited and approved for roll-out nationally. However, the majority of the EPS Release 2 dispensing systems are awaiting technical accreditation followed by further testing in an initial implementation before being approved for roll-out.

The second programme, called ePrescribing, is aimed at hospitals and other acute healthcare settings. In addition to the functions that are part of EPS, ePrescribing has a decision support component. Several institutions have used some form of electronic prescribing for over ten years. Connecting for Health has issued guidelines for evaluating ePrescribing software products, and it has commissioned research to explore the challenges related to, and provide guidelines for, the implementation of ePrescribing.

Challenges for organisation, resources and technology

Currently, there are three broad types of challenges in England for ePrescription, including organisational, resourcing and technological issues:³⁸

From an organisational perspective, healthcare staff must acquire confidence in the technology in order to adopt it. Adopting the technology also means changes to job design and work organisation. This partly results in resistance e.g. of senior hospital clinicians or medical staff to the making of these changes.³⁹

Further challenges include the fact that significant external and internal IT support and healthcare staff time are required for implementation and for training. Training occurs not only prior to implementation but also continues afterwards and is dependent on available resources.

3.3.3 Telemedicine

The use of telemedicine applications is recognised as beneficial to enable access to care from a distance and to reduce the number of General Practitioner visits or even inpatient admissions. Commission services define telemedicine as "the delivery of healthcare

³⁵ NHS Patient Advice and Liaison Service 2006; NHS Connecting for Health March 2010

³⁶ NHS Connecting for Health 2010

³⁷ House of Commons and Health Committee 2010

³⁸ NHS Connecting for Health 2009

³⁹ Evidence for this can be found e.g. in the oral records of the Health Committee of the House of Commons – example: "It is partly to do with the leadership, and my two colleagues here might not agree with me, but it is partly to do with the resistance of senior hospital clinicians to the introduction of changes to their working processes that fundamentally affect them directly ..." (House of Commons 2007)

services through the use of Information and Communication Technologies (ICT) in a situation where the actors are not at the same location^{*40}. In its recent communication on telemedicine for the benefit of patients, healthcare systems and society, the Commission re-emphasises the value of this technology for health system efficiency and the improvement of healthcare delivery⁴¹.

Telemedicine and Telecare services in England are mostly determined at the local level. Currently the following services are developed and available:⁴²

Telecare services

Different alarm systems (including e.g. a personal alarm or motion sensors) Telehealth equipment for home monitoring of e.g. blood pressure, blood glucose

Telemedicine initiatives in England are not combined under a single national programme but rather treated as a combined healthcare and social service that is run at the level of local authorities. Therefore, the Department of Health has provided seed funding for trials of telecare services at local authority level. It is currently funding three demonstrator projects that aim to develop an evidence base for the use of telecare and telehealth in England. Hereby, the Telecare Living and Improving Network⁴³ (LIN) serves as an information repository and an information and news distribution hub for developments in telehealth.

Examples of other national funding initiatives are 1) the Preventive Technology Grant and 2) the Whole System Demonstrator Programme⁴⁴.

The Preventive Technology Grant distributed £80 million in the financial years of 2006/2007 and 2008/2009 to local authorities in order to change the design and delivery of health, social care and housing services. It is said that through the Grant, the number of new telecare and telehealth users have increased by over 200,000.

Examples of concrete telemedicine applications currently running in the NHS England include Teleradiology, where a fully operational Picture Archiving and Communications System - under the aegis of NHS Connecting for Health - enables the digital transmission of radiological images between healthcare providers. The British Teledermatology Society has elaborated an information resource on teledermatology. The Pathology Messaging Implementation Programme (PMIP), which is also managed by NHS Connecting for Health, enables the transmission of digitised pathological results, such as microscopic images of cells, for the purpose of interpretation and/or consultation. Finally, pilot projects in the Doncaster and South Humber Mental Health NHS Foundation Trust should be mentioned as an example of Telepsychiatry services. The Trusts have established

⁴⁰ Europe's Information Society 2009

⁴¹ European Commission 2008

⁴² NHS Choices 2009

⁴³ Telecare LIN was established in 2005 under the auspices of the Health and Social Care Change Agent Team in the Care Service Improvement Service at the Department of Health; it is one of several groups that are collectively known as DH Care Network. (Department of Health , <u>http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Telecare/</u>)

⁴⁴ Department of Health 2009

"eClinics" for psychological therapies for mental health issues such as depression and anxiety.

In 2008, the Whole System Demonstrator (WSD) programme started. It is a two-year research project funded by the Department of Health to find out how technology can help people manage their own health while maintaining their independence. Its results are due to be published in late 2010.

Furthermore, the Department of Health produces an annual report⁴⁵ on research and development work relating to assistive technologies, including telecare and telehealth. The reports are produced for the Department of Health by the Foundation for Assistive Technology⁴⁶ (FAST). FAST is a charity funded by the Department of Health that works with the assistive technology community to promote useful research and development for disabled and older people. The reports include research funded by the United Kingdom Government or the European Union and research projects located in England, Scotland, Wales and Northern Ireland.

Finally the NHS-Direct Service could be considered, at least tenuously by some, as a telemedicine service. The NHS-Direct website provides patients with access to a library of medical advice and the NHS-Direct Telephone assistance service provides patients with a 24-hour service providing health advice and reassurance on the phone⁴⁷. Its benefits include a reduction in inappropriate referrals to direct services such accident and emergency departments or GP/primary care services. It may undergo significant reform within the near future.

Public financing of telemedicine and telehealth services (and eHealth more generally) in England is provided in many forms. Examples include ICT equipment, software, and skills training in eHealth, scholarships for formal education in eHealth, initiation of regional pilot projects, and ongoing support for eHealth programmes. In addition, public-private partnerships in England support the deployment and use of telemedicine and telehealth services. An example of such cooperation is provided by the Continua Health Alliance. Continua is dedicated to establishing a system of interoperable personal health solutions based on a commitment to the fact that extending those solutions into the home fosters independence, empowers individuals, and provides the opportunity for personalised health and wellness management.

For the wellness agenda, for people with chronic diseases, and for telehealth and telecare, the target group(s) for this cooperation are all citizens of England. The NHS is working with Continua to facilitate a system of connected technologies, devices, and services that will enable a more efficient exchange of information on fitness, health, and wellness. This "ecosystem" will be made possible by the creation and implementation of interoperability guidelines which specify how systems and devices produced by different companies can be designed to work together to provide better access to information.

A possible obstacle to telemedicine deployment in England is the loose coordination at national level. Despite some funding support from the Department of Health, local authorities are responsible for evaluating and implementing telecare and telemonitoring.

⁴⁵ Department of Health 2009

⁴⁶ Foundation for Assistive Technology (FAST) 2010

⁴⁷ NHS Direct 2010



While this might allow for the deployment of appropriate solutions at the local level, it does not prevent duplication of effort.

3.4 Technical aspects of implementation

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

3.4.1 Unique identification of patients

National Health Service Number as unique patient ID The NHS number⁴⁸ is the unique patient ID for health purposes in England. In its current 10-digit form, it was formally introduced in 1996. Its foundation is, however, much older⁴⁹. The NHS number is the only unique national patient identifier used by all NHS organisations in England. Babies are given an NHS number at birth and any individual who does not have an NHS number is given one when he or she registers at an NHS general practitioner's surgery or health centre. In addition, an increasing number of Trusts are now able to allocate an NHS Number themselves, usually to overseas visitors who present themselves for treatment in England for the first time.

Use of the NHS Number ensures that a patient's information is linked correctly to different sources as s/he moves through the care system. This reduces risks to patient safety and improves the ease and quality of information transfers across organisational boundaries. The NHS number is provided to patients in a letter or on a medical card when they register with a GP It is also given to a baby at birth or to a person who presents for secondary care if no NHS Number is found for him or her.

Increasingly organisations are including the NHS Number on appointment cards and letters to patients. This approach enables patients to provide their NHS Number when they access NHS services. The NHS Number Information Standardsⁱ approved by the Information Standards Board (ISB)⁵⁰ outline the requirements that organisations must follow to use NHS Numbers correctly.

The NHS Number is stored together, together with other patient demographic information, in the Personal Demographics Service⁵¹ that is a component of the "Spine". The Spine⁵² is the name given to the collection of information technology services and national databases that contains key information about patients' health and care. It forms the core of the NHS Care Records Service⁵³ (NHS CRS). As systems connect to the Spine, the NHS Number provides a means of linking together information from various sources.

⁴⁸ NHS Connecting for Health 2010

⁴⁹ For the history of the NHS number in England see NHS Connecting for Health , <u>http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/staff/history</u>

⁵⁰ Information Standards Board for Health and Social Care

⁵¹ NHS Connecting for Health 2010

⁵² NHS Connecting for Health 2010

⁵³ NHS 2010

3.4.2 Unique identification of healthcare professionals

The identification of healthcare professionals within the NHS Connecting for Health programme in order to access patient data is done via smartcards, issued by registration authorities. All organisations that need to access patient information within the NHS Care Records Service and other National Programmes set up Registration Authorities to manage this process. The Registration Authority is responsible for verifying the identity of healthcare professionals and workers who wish to register to use these services.

Once authorised, individuals are issued an NHS CRS Smartcard by the Registration Authority. Individuals use their NHS CRS Smartcard and their Smartcard Passcode each time they log on. NHS CRS Smartcards help control who accesses the NHS CRS and what level of access that they can have.

A user's Smartcard is printed with the person's name, photograph and unique user identity number. To register for a Smartcard, Registration Authorities are required to ask applicants for identification which satisfies the government recommended standard 'e-Gif Level 3', providing at least three forms of ID (photo and non-photo) and including a proof of address.

Healthcare professionals and other relevant employees are granted access to patient information based on the type of work they do, and their level of involvement in patient care. $^{\rm 54}$

3.4.3 Standards

Standards are not only crucial to enable interoperable exchange of meaningful information in the healthcare system; they also ensure secure access to patient records by healthcare providers and citizens. This study aims to identify, among other usage, standards related to the domain of health informatics, such as the SNOMED Clinical Terms or the LOINC terminology. SNOMED CT (Systematized Nomenclature of Medicine-Clinical Terms) is considered to be the most comprehensive, multilingual clinical healthcare terminology in the world. The organisation developing SNOMED is called the International Health Terminology Standardisation Organisation (IHTSDO⁵⁵).

Overall, the United Kingdom is a member of the IHTSDO. The Department of Health's Informatics Directorate (DHID) is the host of the IHTSDO United Kingdom Terminology Centre (UKTC).

NHS Data Standards & Products

In England, DHID has oversight of health informatics standards which are reflected in NHS Data Standards & Products⁵⁶ (NHS DS&P), which is the responsibility of the Technology Office in DHID; the Technology Office is responsible for the introduction, development and delivery of coding system products used in the patient records of the NHS Care Records Service, and for the phasing-out of dated systems. Principal activities are:

 The NHS Terminology Service⁵⁷ provides support and maintenance for SNOMED CT, Read codes and the Dictionary of Medicines and Devices; it also manages the IHTSDO United Kingdom Terminology Centre (UKTC).

⁵⁴ NHS Connecting for Health 2010

⁵⁵ International Health Terminology Standards Development Organisation (IHTSDO)

⁵⁶ NHS Connecting for Health 2010



- The NHS Classifications Service⁵⁸ provides support and maintenance for OPCS4 and ICD-10.
- The NHS Data Model and Dictionary Service⁵⁹ provides the development, maintenance and support of NHS data standards.
- The Standards Consulting Group⁶⁰ provides guidance and assistance to NHS Connecting for Health programmes in the development and implementation of standards in a consistent manner.
- The Information Governance Group⁶¹ Information Governance ensures necessary safeguards for, and appropriate use of, patient and personal information.

Although it lies outside of the NHS Data Standards and Products group, a Health Informatics Service Benchmarking and Accreditation Scheme was developed and launched in 2008.⁶². Its aim is to help health informatics providers and Information, Management & Technology departments to develop services that are quality-assured and "fit for purpose".

The following standards are currently used in England (the list includes United Kingdomdeveloped standards).⁶³

Standards used in England:

HL7 v3: This forms the basis of all clinical communication between Connecting for Health systems.

Clinical Document Architecture (CDA): is a document mark-up standard, based on HL7 v3, used when transferring clinical information as documents rather than messages.

SNOMED-CT.

ICD 10.

OPCS-4 Intervention Classification: Current version is OPCS-4.5

Read codes: Support provided for all versions of the Read Codes, including the Drug and Appliance Dictionary.

Dictionary of medicines + devices (dm+d): dm+d is a dictionary containing unique identifiers and associated textual descriptions for medicines and medical

⁵⁷ NHS Connecting for Health 2010

⁵⁸ NHS Connecting for Health 2010

⁵⁹ NHS Connecting for Health 2010

⁶⁰ NHS Connecting for Health 2010

⁶¹ NHS Connecting for Health 2010

⁶² NHS Connecting for Health 2010

⁶³ NHS Connecting for Health 2010



devices. It has been developed for use throughout the NHS (in both primary and secondary care) as a means of uniquely identifying the specific medicines or devices used in the diagnosis or treatment of patients. (Release 2 version 3.0, April 2010).

The main challenges related to standards development in the NHS England will be not only retaining the resources (both financial and professional) to deal with the diverse range of healthcare informatics services but also finding new money for future initiatives and investment. Continuing professional development of such staff is also important, and organisations such as the United Kingdom Council for Health Informatics Professions might help to achieve this.

3.5 Legal and regulatory facilitators

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

Most health legislation relating to England since 1977 was consolidated in two acts of parliament that came into effect on 1 March 2007.

Joint guidance on the use of IT equipment and access to patient data

On 25 April 2007, the Department of Health, the General Medical Council and the Office of the Information Commissioner issued "Joint guidance on the use of IT equipment and access to patient data"⁶⁴. This document pointed out the need to comply with duties of confidentiality that are a part of the code of conduct of the regulatory bodies that govern registered health professionals. The document also draws attention to two other relevant guides issued by the Department of Health: Confidentiality: NHS Code of Conduct⁶⁵ (November 2003) and the Care Record Guarantee⁶⁶ (first published May 2005, and subsequently updated). Within those two documents, attention was drawn to people's access rights to their own records, controls on others' access, the options people have to further limit access, and access rights in case of an emergency.

The joint guidance on the use of IT equipment and access to patient data cited three specific legal standards:

- The Human Rights Act 1998, especially Article 8.
- The Data Protection Act 1998, especially the 1st and 7th Principles, and Section 55.
- The Common Law⁶⁷ of Confidentiality.

⁶⁴ Department of Health 25.04.2007

⁶⁵ Department of Health 2003

⁶⁶ Health Minister Lord Warner

⁶⁷ "Although not codified in an Act of Parliament, common law is built up from case law where practice has been established by individual judgements. The key principle is that information confided for the purpose of receiving care and treatment should not be processed for other purposes except in circumstances where the law permits or requires it."

The Department of Health has also issued guidance entitled Records Management: NHS Code of Practice Part 1 (April 2006) and Part 2 (January 2009). This "is a guide to the required standards of practice in the management of records for those who work within or under contract to NHS organisations in England. It is based on current legal requirements and professional best practice". The code makes, for example, recommendations on the minimum periods for which different forms of medical records should be retained.

NHS Connecting for Health has provided supplementary information, NHS Records Management: A clinicians' guide to record standards, which contains "a range of practical tools and guidance designed to support organisations in the implementation of an effective records management system in line with the principles of Records Management: NHS Code of Practice".

Digital, personal demographic, and health data are stored centrally on the NPfIT component known as the Spine. Direct access to the Spine or to services that access these data are controlled by the Access Control Framework. Organisations that need to access patient information within the NHS Care Records Service (NHS CRS) and other National Programmes set up Registration Authorities to manage this process. Once authorised, individuals are issued an NHS CRS Smartcard by the Registration Authority. Individuals use their NHS CRS Smartcard and their Smartcard Passcode each time they log on. Individual access is further restricted according to a Role-based Access Control that is assigned when a smartcard is issued.

With regard to ePrescription applications, some legislative changes were required in England. Traditionally prescriptions have been issued on approved paper forms and had to be signed with ink. The National Health Service Pharmaceutical Services Regulations of 2005 now provide that when prescribed to an Electronic Transfer of Prescription service and with the patient's consent healthcare providers may also issue their prescriptions electronically.

Telemedicine as a specific concept is not further regulated. Although, in a different context, the question of whether a doctor is obliged to physically attend a patient did arise in the United Kingdom, there does not seem to be any general principle requiring this.

In terms of telemedicine applications in England, there is no specific accreditation for health professionals who are involved in the provision of telemedicine services to patients. However, all medical doctors undergo continuing education and upgrade their skills in a wide range of different fields. Continuing education is strongly promoted by all of the regulatory bodies in the United Kingdom that govern health professionals in England. Furthermore, the British Medical Association has made its own recommendations with regard to the need for training in the field of supporting self care on the part of patients (however, there is no direct correlation made in the text between self care and home care in an electronic sense). These recommendations are:

- "Education on facilitating self care should be included in the medical curriculum including awareness of the fragility of self care and how it can be strengthened. Training should also be provided for practising doctors on the appropriate consultation techniques for patients with long term conditions."⁶⁸
- "Healthcare professionals should be rewarded for undertaking learning and skills development for long term support of self management."

⁶⁸ British Medical Association 2007



Patient rights

"Your health information and the NHS Care Records Service"

Patients' rights with regard to their personal data are comprehensively set out in various sources in England. They are described in "Your health information, confidentiality and the NHS Care Records Service"⁶⁹ (April 2008) and in the "NHS Care Record Guarantee"⁷⁰ (July 2009) and under the Data Protection and Access to Health Records Acts. A patient/person has the right to apply for access to his/her data or request a copy of the data based on payment of an administrative fee. A patient can ask to see information about who has had access to his/her Summary Care Record. If any item of information is not readily intelligible to the patient, further explanation must accompany the record.

In England, the concepts of patient confidentiality and consent are significant for the provision of care. Legislation, such as the Data Protection Act, and common law do not define these concepts but provide frameworks for processing information on a patient's care.

An example is the summary care record. Policy makers have opted for an implied consent model. Patients are notified in writing that a summary care record will be created for them unless they opt out within a limited period (between two to three months).

A patient can add or change some demographic information and other non-clinical information on the electronic patient record: see Your health information, confidentiality and the NHS Care Records Service (April 2008, pp.11-12). This facility is provided through a web-based service called NHS HealthSpace although it is also possible for such changes to be made via a patient's GP.

Furthermore, patients cannot change information that other people write to the record; however, they can ask staff to correct mistakes. If the staff member thinks that the information is correct, a patient can add a statement to say that s/he disagrees. The National Information Governance Board has produced Guidance on Requesting amendments to health and social care records⁷¹.

In the future, a patient will be able to ask for certain information to be hidden. This may be done through a "patient's sealed envelope" although the final details are still under consideration. Using this feature, if a patient "seals" some information, no-one outside of the care team that sealed the information will able to see what has been hidden. However, a flag associated with the patient record will indicate that some information has been hidden. If information is "sealed and locked" by a care team, it will be completely invisible to anyone outside of that care team.

Procedures to allow access to the summary care records are defined

Procedures to allow access to certain people other than the patient are also described in "Your health information, confidentiality and the NHS Care Records Service"⁷² and in the "NHS Care Record Guarantee"⁷³. The patient is advised to speak to a healthcare professional to decide which information to make available, to whom, and in what circumstances. Furthermore, at present, parents or guardians of children under 16 have

⁶⁹ NHS Connecting for Health 2008

⁷⁰ Health Minister Lord Warner

⁷¹ National Governance Board for Health and Social Care 2010

⁷² NHS Connecting for Health 2008, p.12-16

⁷³ NHS Connecting for Health 2009, p.6 and p.12-13

the right to access their child's records. Although a child can ask that the parents or guardians not be given access, this request might be overruled if the reasons given for access are more important than the requirement to keep child's information confidential. The Access to Medical Records Act (1990) provides an explicit right of access to medical records of deceased persons.

There are circumstances in which the NHS can use patient data for purposes than the provision of healthcare. In some cases, such as an application for medical insurance, the patient must give explicit consent to allow the insurer to see the patient record. The patient can also limit which information can be accessed (Confidentiality, p.14). In other cases, such as anonymised research or to protect public health, the information can be used without patient consent (Confidentiality, p.4, Guarantee p.1, pp.5-7). In limited circumstances, the Secretary of State for Health can give permission to the use patient of information without asking for permission (Confidentiality, p.5), for example, in the conduct of important health research where it is not practical to contact all of the patients.

3.6 Financing and reimbursement issues

In England, the Department of Health funds the vast majority of the eHealth infrastructure. It is possible though that some county councils and local authorities, through their social services budget, fund part of the operational costs of local telecare and telehealth services.

More precisely, the Department of Health has an overall annual budget of approximately £100 billion. The projected costs of the National Programme for IT^{74} from 2003/04 to 2013/14 were £12.7 billion at 2004/05 prices. To 31 March 2009, £4.5 billion had been spent. Some detail is provided in *Table 1* which is taken from Public Expenditure on Health and Personal Social Services 2009, written evidence to the Health Committee of the House of Commons (January 2010).

The table below summarises the English expenditure on health and personal social services. All figures in the table are in GBP millions.

⁷⁴ National Audit Office 2008

eHealth

	Category	Projected lifetime costs	Expenditure to 31 March 2009
Core Contracts			
	London	1,021	326
	South	1,104	133
	North East	1,035	276
	East	930	237
	North West & West Midlands	1,042	271
	Spine	889	791
	N3 Network	554	554
	Choose and Book	144	133
	Amount retained by Accenture ⁷⁷	110	-52
Total core contracts		6,829	
	Products added to scope	666	420
	Other central costs	1,599	615
Total central costs		9,094	
	Local costs (estimated) ⁷⁸	3,562	772
Total		12,656	4,476

	75							76
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⁷⁶ Health Committee 2010

⁷⁵ **Notes related to the table:** The figures shown in the last two columns are not directly comparable, as the projected lifetime costs are shown at 2004/05 prices and final outturn will be higher due to inflation in subsequent years. Those for expenditure to 31 March 2009 are resource outturn figures.

As for London, South, North East, North West & West Midlands, these geographical areas correspond to contracts with major suppliers (Local Service Providers) who work with the NHS to deliver the National Programme for IT systems and services at the local level, including the NHS Care Records Service. The **Spine** is a group of eight applications which underpins the NHS Care Records Service – three applications hold care record data; four are security applications to restrict access to only accredited users; and one is a messaging service, providing interfaces between Spine data and other services. The New **NHS Network** (N3) provides IT infrastructure, network services and broadband connectivity linking every NHS site in England including hospitals and general practitioner surgeries, and non-NHS sites providing NHS care.

Further, **Choose and Book** is the national electronic referral service which gives patients a choice of time and place for their first outpatient appointment, and allows the appointment to be booked using the Internet, a telephone booking service or a general practitioner's IT system. **Products added to scope** are applications and services that have been added during the course of the programme. These include GP Systems Choice which allows general practitioners to choose an approved clinical IT system other than the one offered by the Local Service Provider. An NHS email system, NHSmail was also added.

Additionally, **local costs** are the costs incurred by local NHS bodies to implement the systems (principally the new Care Records Service and the Picture Archiving and Communications Systems), for example in training staff and upgrading computer hardware. These estimates have not been revised since the original business cases were submitted in 2003/04.

⁷⁷ In 2006, Accenture made arrangements to voluntarily novate [assign] the company's contract to another existing supplier under the programme. Of the £179 million Accenture had received to that point the company retained £110 million for work completed. £52 million represents the value, for accounting purposes, of moneys repaid as at 31 March 2009.

⁷⁸ No figures have been received to date for local costs for period 2008-09 and therefore the figure is retained as per 2008 return.

Connecting for Health has regularly been criticised in the United Kingdom press for the relative size and volume of its initiative, and the generous allocation of financing to it. Its approach has at times been compared unfavourably to more incremental, smaller initiatives in countries with much smaller populations (e.g., those of Scotland and/or Wales).

In terms of international funding opportunities, England received financing by the European Commission through a variety of Framework Programmes, the European Regional Fund, the European Social Fund and other programmes. England has especially been an active participant in the large-scale pilot on eHealth interoperability called epSOS⁷⁹, and its accompanying thematic network which is known as CALLIOPE⁸⁰.

Challenges for eHealth financing

Future challenges will particularly lie in the capacity to continue to pour funding into NHS England as a whole (a difficulty raised by all England's political parties prior to the May 2010 election, but which it is fully anticipated that the government of the day will emphasise and a challenge that it will attempt to resolve). It is perhaps expected that 2010 and ensuing years will see both a reduction in NHS England budget, and the budget of Connecting for Health.

3.7 Evaluation results, plans and activities

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

Different evaluations completed and ongoing in cooperation with research groups Since 2006, two eHealth evaluations in England have been completed and six further evaluations are ongoing. All of these evaluations have been or are undertaken by staff and researchers from one or more United Kingdom universities. The research group is selected on the basis of research submissions that were submitted in response to a call for proposals (issued by the University of Birmingham on behalf of the NHS Connecting for Health Evaluation Programme⁸¹).

The NHS Connecting for Health Evaluation Programme⁸² was commissioned by NHS Connecting for Health (NHS CFH) through the Research and Development Directorate of the Department of Health. It was set up at the end of April 2006 to evaluate certain elements of the NPfIT delivery. It aims to inform subsequent deployments of technologies and to provide high quality, objective, third-party insights into the lessons learned as a result of such large-scale projects.

The Public Health, Epidemiology and Biostatistics Unit of the School of Health & Population Sciences at the University of Birmingham have been commissioned by NHS CFH to manage the evaluation programme on its behalf. This management of the programme includes two aspects: the independent procurement ("commissioning") of

⁷⁹ Smart Open Services for European Patients

⁸⁰ Calliope Network

⁸¹ University of Birmingham

⁸² NHS Connecting for Health 2010



evaluation services, and the day-to-day management of the independent organisations which actually conduct the evaluations.

Evaluation projects of eHealth activities⁸³:

Completed:

NHS CFHEP 001: The Impact of eHealth on the Quality and Safety of Healthcare

NHS CFHEP 002: Evaluating the 'Early Adopter' implementation of the NHS Summary Care Record

Ongoing:

NHS CFHEP 001: Extension to The Impact of eHealth on the Quality and Safety of Healthcare

NHS CFHEP 003: Evaluation of the pilot implementation of an IT specification for a blood tracking systems

NHS CFHEP 004: Evaluation of the Electronic Prescription Service in Primary Care. This project has set up a web site to provide users and designers of the Electronic Prescription Service a forum to exchange their experiences, lessons and views of the EPS.

NHS CFHEP 005: Evaluation of the adoption of the NHS Care Record Service in secondary care

NHS CFHEP 007: Summary Care Record Independent Evaluation (SCRIE) Extension Programme

NHS CFHEP 009: Evaluation of different levels of structuring within the clinical record

NHS CFHEP 010: Evaluation of the effect of IT on interactions between healthcare workers and patients

The National Audit Office⁸⁴ has conducted two reviews of the National Programme. It published a document entitled "Department of Health: The National Programme for IT in the NHS"⁸⁵ (on June 16 2006). This was an assessment of the programme which took place around two years after its inception. The conclusions and recommendations in the report addressed challenges in three key areas:

- Ensuring that the IT suppliers continue to deliver systems that meet the needs of the NHS, and to agreed timescales without further slippage.

⁸³ List of the evaluation projects on this website: University of Birmingham <u>http://www.haps.bham.ac.uk/publichealth/cfhep/research.shtml</u>

⁸⁴ The NAO (<u>http://www.nao.org.uk/</u>) has the job of auditing the accounts of all government departments and agencies as well as a wide range of other public bodies. The Office reports to Parliament on the economy, efficiency, and effectiveness with which these bodies have used public money. Its head, the Comptroller and Auditor General, is an Officer of the House of Commons, appointed by the Queen, proposed by the Prime Minister with the agreement of the Chairman of the Committee of Public Accounts, and approved by the House of Commons. The role is an independent one; his/her staff carries out these auditing task on his/her behalf. The NAO undertakes around sixty value-for-money studies each year. This forms part of its overall aim to enable Parliament and government to drive through lasting improvements in public services. The reports are presented to Parliament, and most are considered by (i.e., reviewed by) the Public Accounts Committee of the House of Commons (PAC).

⁸⁵ National Audit Office 2006



- Ensuring that NHS organisations can and do fully play their part in implementing the Programme's systems.
- Winning the support of NHS staff and the public in making the best use of the systems to improve services.

Two years later, in 2008, the National Audit Office published a document entitled "The National Programme for IT in the NHS: Progress since 2006^{*86} (May 16 2008). Although this was largely a value-for-money review, it did consider technical issues, and it examined how the implementation of new technology affected organisations, staff and patients.

By 2008, with more parts of the NHS involved in activities related to the National Programme for IT, the conclusions and recommendations addressed a similar set of challenges to the three problems outlined above:

Recommendations outlined by the National Audit Office

Achieving strong leadership and governance [within the Strategic Health Authorities and NHS Trusts]

Maintaining the confidence of patients that their records will be secure

Securing the support and involvement of clinicians and other NHS staff

Managing suppliers effectively

Deploying and using systems effectively at local level.

4 Outlook

The NHS has created or has started to create different eHealth applications in England, including the Summary Care Record or locally-organised telemedicine services. The NHS Connecting for Health was established in order to supervise and deliver the National Programme for IT. Connecting for Health is also the link between the Department of Health, stakeholders, healthcare professionals, and the patient. It provides a variety of information websites which clarify new developments or applications for the patient.

Overall, England pursues a transparent development and implementation of eHealth services. Future obstacles might involve the content of the Summary Care Record or the validation of a professional identifier. Nevertheless, England is heading towards a more patient-empowered approach, as the introduction of a "patient's sealed envelope" indicates.

Following elections in the UK in May 2010, the set-up of the NHS is under important review. The policy changes at hand will impact on the eHealth policy in NHS England. These changes are taken into account in this report to the extent that they are already discernible today in October 2010. However, much of this report focuses on the organisational conditions that prevailed in the NHS at the time that the first draft of this report was finalised (in early May, 2010).

⁸⁶ National Audit Office 2006



5 List of abbreviations

DHID	Department for Health Informatics Directorate
DRG	Diagnosis Related Group
EC	European Commission
EEA	European Economic Area
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPS	Electronic Prescription Service
ERA	European Research Area
EU	European Union
FAST	Foundation for Assistive Technology
GDP	Gross Domestic Product
GP	General Practitioner
НСР	Healthcare Provider
HPC	Health Professional Card
ICT	Information and Communication Technology
ID	Identification (e.g. number, card or code)
IHTSDO	International Health Terminology Standards Development Organisation
ISB	Information Standards Board
IT	Information Technology
LIN	Telecare Living and Improving Network
NHS	National Heath Service
NHS CFH	National Health Service Connecting for Health
NHS CFHEP	National Health Service Connecting for Health Evaluation
	Programme
NHS CRS	National Health Service Care Records Service
NHS DS&P	National Health Service Data Standards and Products
NPfIT	National Programme for Information Technology
OECD	Organisation for Economic Co-operation and Development
PCTs	Primary Care Trusts
PDS	Personal Demographics Service
PHS	Personal Health System
NPfIT OECD PCTs	National Programme for Information Technology Organisation for Economic Co-operation and Develops Primary Care Trusts

PMIP	Pathology Messaging Implementation Programme
PSIs	Personal Spine Information Service
R&D	Research and Development
SCR	Summary Care Record
SCRIE	Summary Care Record Independent Evaluation
SHAs	Strategic Health Authorities
UKTC	United Kingdom Terminology Centre
WHO	World Health Organization
WSD	Whole System Demonstrator



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