

Country Brief: Iceland

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About the eHealth Strategies study

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

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Executive summary

Regarding eHealth in Iceland two policy papers are of importance: The project plan for building a health network, which was published in 2000 and the National Health Plan¹ from 2004. The National Health Plan refers to both European and Icelandic targets, it also uses statistical measurement tools to present a reasonably accurate picture of the development of healthcare matters. In addition, the plan covers specific factors which influence the making and implementation of health plans

A more recent strategy that – among other things – also draws upon eHealth applications is "Iceland the e-Nation (2008-2012)"². This includes a vision of Iceland as the leading nation in electronic services and the utilisation of information technology. In addition to this objective, the government has established goals in various specific areas which are also important to pursue while implementing the policy.

In order to consider Iceland'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 Iceland's situation is as follows:

In Iceland the electronic health record system (Saga system) operates via the communication framework Healthnet. As all healthcare centres use the same software, and harmonisation of records has been applied, there is coordination among centres and integration of information.

Iceland has a national ePrescription system. All healthcare facilities are connected to a single administrative entity which enables the transmission of prescriptions to pharmacies.

Iceland uses international standards and employs the Directorate of Health for the translation and update of healthcare coding and classification systems nationally.

Through different telemedicine projects new applications and services were and still are constantly being developed. The projects include teleradiology, teleobstetrics, telepsychiatry, maritime telemedicine, telemedicine in surgery, telepathology and projects for the use of telemedicine in various consultations.

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¹ The Ministry of Health and Social Security 2004

² Prime Minister's Office 2008



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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", 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 Initiative⁴ 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* 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. With the involvement of almost all Member States, its goal is to define and implement a European wide standard for such applications at the interface between national health systems.

Earlier, in line with the requirement to "regularly monitor the state of the art in deployment of eHealth", the EC already funded a first project to map national eHealth strategies – the eHealth ERA "Towards the establishment of a European eHealth Research Area" (FP6 Coordination Action)⁸ - and a project on "Good eHealth: Study on the exchange of good

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 eHealth Priorities and Strategies in European Countries 2007



practices in eHealth" 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 Iceland 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 Iceland, 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 key tool to collect this information from the correspondents was an online survey template containing six main sections:

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

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

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

¹⁰ National Institute for Health and Welfare



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 Iceland 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.

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1.3 Outline

At the outset and as an introduction, the report provides in chapter 2 general background information on the *Icelandic* 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 introduction¹¹

Iceland is an island in the North Atlantic Ocean, northwest of the British Isles. An area of 103.000 km² makes it somewhat larger than Portugal or Hungary. With 317.593 inhabitants in 2009, it is the most sparsely populated country in Europe, averaging 3.1 inhabitants per km².

Iceland is a parliamentary democracy with a prime minister and a cabinet. A president is elected by direct vote for a term of four years, with no limit on re-election. Legislative power is vested in the parliament, the Althingi. Parliamentary elections are held every four years. The present government was elected in April 2009. At the moment the Social Democratic Alliance forms a minority coalition with the Left-Green Movement and the support of the Progressive Party and the Liberal Party.

The Icelandic healthcare system can be described as universal, comprehensive and mostly financed by general taxation. The Health Services Act that came into force on 1 January 1974 accorded all citizens of Iceland access to the best health services at any given time for the protection of their mental, physical and social health. It laid the groundwork for the present organisation of the health services and defined the structure of the healthcare centres and the hospital system.

Furthermore, the country is divided into healthcare regions, each with their own primary healthcare centres, some of which are run jointly with the local community hospital. The primary healthcare centres have the responsibility for general treatment and care, examination, home nursing as well as preventive measures such as family planning, maternity care and child healthcare and school healthcare.

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

Key facts about the Icelandic healthcare system: 12

Life expectancy at birth: 81.6 years

Healthcare expenditure as % of GDP: 9.3% (OECD 2007)

WHO ranking of healthcare systems: rank 15

Public sector healthcare expenditure as % of total healthcare expenditure: 83%

(OECD 2007)

¹¹ Ministry of Health; Halldorsson 2003

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



2.2 Healthcare governance¹³

Decision making bodies, responsibilities, sharing of power

In Iceland, the Minister of Health and Social Security is ultimately responsible for the administration of health services. Thereby, the Ministry, led by the Permanent Secretary, is organised into seven departments:

- Department of Finance
- Department of Legal Issues
- Department of Social Security Legal Issues
- Department of Social Security Welfare Issues
- Department of Primary Care, Hospitals and Care of the Elderly
- Department of Pharmaceuticals
- Department of Planning and Development.

The seven departments are responsible for the administrative work on the key functions of the healthcare system and social security that lie within their division, and for guiding and harmonising actual activities in the health sector.

The Medical Director of Health serves as adviser to the Minister and to the government on everything concerning health. He supervises the activities and the working facilities of health professionals, collects statistical reports and is in charge of the publication of the country's health statistics in cooperation with the Ministry of Health and Social Security.

The Directorate of Health is obliged to deal with complaints or charges arising from the relations between the general public and the health services. People can also present their complaints to a committee that has no connection to the health authorities and is chaired by a lawyer.

The State Social Security Institute (SSSI) is charged with the administration of pension insurance, occupational injury insurance and health insurance in accordance with the Act on Social Security. Each branch of insurance has its separate finances and constitutes an independent department within the SSSI. The parliament elects five persons to the Social Security Board (SSB), and the Minister appoints a chair from their number. The SSB supervises the finances, operation and activities of the SSSI. Disputes arising with respect to the basis, conditions or amount of benefits are adjudicated by an independent committee, the Social Security Ruling Committee.

Healthcare service providers

Healthcare centres throughout the country provide primary care. This arrangement was a major reform of the Health Service Act that came into force in 1974. Before that time, curative healthcare was provided by general practitioners in individual practices. Remnants of the old system still exist to a small degree in Reykjavík, where some 10 private practitioners provide such care and get paid according to the number of patients on their list as well as fee-for-service.

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¹³ Halldorsson 2003



No new private practice agreements for general practitioners have been made for many years. It has been the policy of the health authorities that all primary care will be provided by the healthcare centres in the future. The reasons behind this policy are mainly that preventive services are considered an important part of primary healthcare and that primary healthcare is essentially teamwork, with the doctor only a part of the team.

Most specialist outpatient care is provided by private practitioners working on their own or in rented premises, sometimes in group practice. The private practitioners are the most rapidly growing part of the healthcare sector regarding volume. They work on a fee-for-service basis negotiated by the medical association and the health authorities.

Ambulatory care within hospital care, on the other hand, is less common than in neighbouring countries. Until 1998, outpatient hospital care was also paid for by the SSSI, but since that time it has been paid of the hospitals' fixed budget, which has increased correspondingly. Many private practitioners work part time as salaried doctors in the hospitals.

Hospitals fall into seven categories according to Icelandic law, but only the first two or three are hospitals in the traditional sense of the word: regional hospitals, hospitals with several departments and so-called general hospitals, with specialists in surgery, medicine or general practice. Many of the general hospitals are now primarily nursing homes, with only a few beds for observation and simple medical treatment. The other categories include nursing homes, rehabilitation institutes, homes for the chronically ill and institutions for the rehabilitation of alcoholics and other drug addicts.

Institutions in these categories are mostly owned and run privately but financed by the SSSI or directly by the state. Approximately 94% of rehabilitation services are privately run, as well as 60% of the institutions and services for old people outside acute hospitals. Influential institutions in the field of prevention are also run by private NGOs, such as the Cancer Society and the Icelandic Heart Association, but with considerable public support. The first health institution to be constructed and run by a for-profit enterprise is a very modern nursing home with 90 beds that began operating in 2002. There is no discrimination in access to this nursing home in terms of income or social status, the deciding factor being health status.



Figure 1: Important features of primary healthcare organisation in Iceland

Political/administrative unit responsible for primary healthcare	Ministry of Health and Social Security is ultimately responsible for the administration of health services. One of the seven departments of the Ministry is the department of primary care, hospitals and care of the elderly. Iceland is split into different healthcare districts and each one is responsible for its healthcare centres, which are called heilsugaeslustod. Some of the centres are run together with the local hospital. Thereby, primary healthcare is divided into eight regions, which are subdivided into 31 areas with a total of 83 health centres. Of these, nine are in Reykjavik.	
Consumer Choice	Each citizen is required to register with a GP. Those who live in the capital, Reykjavík may register with a self-employed family practitioner. In each area, there is a doctor on-call 24 hours a day.	
Financing	The Icelandic healthcare system is mainly financed by general taxation (taxes cover 85% and 15% is fee for service). The government decides the level of fees. Fees are charged for treatment at the health centres and hospital outpatient care. However, there are no fees for inpatient treatment. The state can contract out the activities of the healthcare centres, and the first tender for a totally privately run healthcare centre was launched in the beginning of 2003. The services provided will be the same as in the state-run centres.	
Public or private providers		
Gatekeeping function of the GP	The Icelandic social security system is open. There is free access to all physicians. When patients seek secondary medical help this is not supplied in the hospital ambulatory wards but by specialists in private practices. The patient may get a referral letter from his or her family physician or seek out the specialist him or herself. The authorities try only to direct the flow by having patients pay a lower amount to the family physician than to the specialist. However, both amounts are low and become even lower if the cost per individual exceeds a certain limit per annum.	
Integrating health: initiatives for coordination	Some of the health centres are run together with the local hospital. All healthcare centres are visited on a regular basis by opticians, gynaecologists, ear nose and throat specialists and paediatricians. The need for more cooperation between GPs and the hospital emergency and accident service has been identified as a future target for the provision of out-of-office hours services.	



2.3 Recent reforms and priorities of health system/public health

In the 1970s, 1980s and 1990s, the Icelandic healthcare system underwent several major reforms. Some of these reforms have been prompted by new technology and better communications. In primary care, the previous system, which consisted largely of primary practitioners working alone, has been replaced by a network of well equipped healthcare centres, which are staffed by specially educated general practitioners (GPs) and nurses, and which in many cases provide other services as well, such as simple laboratory and X-ray services, dentistry and physiotherapy. Small urban hospitals have been turned into nursing homes, with a few acute beds for simple medical treatment, but no surgical facilities. Specialists from the larger hospitals now serve some of the rural hospitals. There are now only two hospitals outside the capital that provide a wide selection of medical specialties. On-call services in medicine, surgery and gynaecology will probably in the near future only be provided in a few rural towns where it is essential for geographical reasons. In 2000 three acute hospitals in the capital were merged into one strong university hospital. An agreement between this hospital (Landspítali University Hospital) and the University of Iceland promises closer future cooperation between these institutions in the fields of research and education. 14

Currently ongoing reforms in the health and social care systems¹⁵

The last quarter of 2008 was severely affected by the economic disaster that hit the country in the beginning of October. The health services were required to take immediate measures to save 6.7 billion ISK, no less. Already in October, the Medical Director of Health submitted to the Minister of Health his ideas regarding vulnerable aspects of the healthcare service that would need to be protected as far as possible, especially primary and mental healthcare. He particularly emphasised the need for protecting geriatric health services and proposed instead that overtime and similar items be cut down. There is every indication that demands for cut-downs will be more difficult and will result in some reduction in the health services.

In October, the Medical Director of Health summoned a group of healthcare managers and scholars in order to monitor closely the attendance rates in healthcare services following the financial collapse. This group of 10-12 experts has met regularly since then.

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¹⁴ Halldorsson 2003

¹⁵ Halldórsson 2008



2.4 ICT use among general practitioners

This section will give a brief overview of important ICT related infrastructure and services data. It draws on earlier studies conducted by empirica, notably the Indicators eHealth study¹⁶.

In terms of infrastructure, 99% of the Icelandic GP practices use a computer and 98% of the practices dispose of an Internet connection. In Iceland, broadband represents the usual form of access to the Internet with 86% of GP practices resorting to broadband connections.

The storage of electronic medical patient data is common practice in Iceland. Nearly all GP practices store at least one type of individual data.

A computer is available in the consultation room in 97% of the Icelandic GP practices. Here it could for instance be used to display a patient's file to the practitioner, to explain medical issues to the patient by means of a photo or animation but also to run a Decision Support System helping in diagnosis or prescribing. In Iceland around 85% of the practices actually use a computer for consultation purposes. Thus a certain "availability versus use" gap can be discerned.. A Decision Support System is used in 69% of the Icelandic GP practices.

The exchange of electronic patient information via the Internet or other dedicated networks is comparatively common in Iceland. 17% of the practices exchange medical data with other care providers or professionals. 52% of GP practices in Iceland receive laboratory results in digital form.

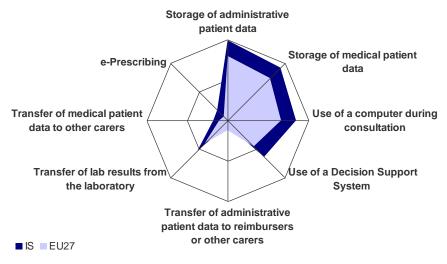
ePrescribing is used by 18% of GP practices in Iceland.

12% of the Icelandic GP practices exchange administrative data with other carers, as compared to the average rate of 10%. The only type of data exchange which is considerably less used in Iceland is the exchange of administrative data with reimbursers: with a usage rate of only 1%.

¹⁶ ICT and eHealth use among General Practitioners in Europe 2007



Figure 2¹⁷: eHealth use by GPs in Iceland



Indicators: Compound indicators of eHealth use (cf. annex for more information), % values. Source: empirica, Pilot on eHealth Indicators, 2007.

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 Iceland are presented. This is followed by a presentation of administrative and organisational measures taken. Section 3.3 presents results on key eHealth applications. Section 3.4 focuses on the technical side of eHealth, namely the role of patient and healthcare provider identifiers and the role of eCards. Legal and regulatory facilitators as well as financing and reimbursement issues are presented in the following chapters, 3.5 and 3.6. The report concludes with evaluation activities (3.7) in the country and an outlook (4.).

3.1 eHealth policy action

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

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 www.ehealth-indicators.eu.



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

4.1.1 Current strategy/roadmap

For the Icelandic health system development, two policy papers are of importance: 1) The project plan for building a health network, which was published in 2000 and 2) the National Health Plan¹⁸ from 2004. A more recent strategy that – among other things – also draws upon eHealth applications is "Iceland the e-Nation (2008-2012)" 19.

The project plan for the establishment of the health network, the so-called "heilsunet" is rated as one of the most effective initiatives in Iceland for building an ICT infrastructure. Within the "heilsunet" initiative consumer health informatics are seen as a central issue for growing awareness of the importance of professional information techniques to improve the health information treatment and equalise consumers' and health professionals' relationship. The conceptual model (as seen on the right) is visualised as a plant symbolic of healthcare and insurance services resting on consumer health informatics as the basis of quality and successes. The plant represents a holistic approach to consumer-driven healthcare and insurance services.

Project Plan for a Health Network "Heilsunet" (2000)

National Health Plan

Iceland the e-Nation 2008-2013

The National Health Plan for Iceland from 2004 describes all the European targets, circumstances in Europe and in Iceland, and the specific Icelandic targets up until 2010. It also covers fields where the situation is unsatisfactory, or less clear. Furthermore, the Plan uses statistical measurement tools, thereby endeavouring to present a reasonably accurate picture of the development of healthcare matters and of the effectiveness of the country's healthcare services. The Plan covers specific factors which influence the making and implementation of health plans. Among these are trends in population growth, age composition, lifestyle and environment, the economic situation, state fiscal status, quality of healthcare services, social services, progress in medicine and other healthcare sciences, the description of the general health situation and future vision for healthcare affairs as well as technological development in the field of health. In detail it is aiming for promoting an increase in healthcare technology industry turnover to one-third of public expenditure on healthcare services.

In 2008, the "Iceland the e-Nation" plan was published. It envisages that Iceland should become the leading nation in electronic services and the utilisation of information technology. In addition to this objective, the government has established goals in various specific areas which are also important to pursue while implementing the policy. This includes the plans of the Ministry of Health to develop and implement electronic medical records and a health net.

Earlier documents, which are concerned with IT in healthcare and information society plans in general, include the following:

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¹⁸ The Ministry of Health and Social Security 2004

¹⁹ Prime Minister's Office 2008

²⁰ Heilsunet



- Strategic Policy Document on Information Policy in the Healthcare System (1998)
- Government Declaration for Policy on the Information Society (1996)
- eGovernment Information Society 2004-2007

Especially the latter draws upon the use of information technology in all sectors, including specific goals such as the establishment of a "Healthnet", introduction of electronic patient records for all healthcare services and enabling electronic transactions between the State Social Security Institute, healthcare workers and the public.

The strategic policy document from 1998 was published by the Ministry of Health. It includes the following items: use of IT in healthcare, data security and data storage, privacy, public access to healthcare information and the use of standards.

The Government Declaration served as a basis for the information society plans which followed in 2004 and 2008 by defining main issues in relation to the utilisation of technology. For healthcare it is defined that good access for citizens to healthcare services should be provided, that privacy and security should be maintained with the use of IT and that the quality and economics in healthcare services should be increased.

Figure 3 summarises Icelandic policy documents related to eHealth

2000 2004 The project plan defines health The plan from 2004 draws upon informatics as central issue for the use of technology in the the improvement of health healthcare sector and emphasises information treatment and the goal of establishing a consumer-driven healthcare. Healthnet for Iceland. "Strategic Policy "Icelandic "Project Plan for a Health Network ,Heilsunet" eGovernment Document on Information
Policy in the Healthcare
System" National Health .lceland the e-Information Society Plan' Plan to the year 2010" 1998 2004 2008 The policy document was published by The Health Plan describes specific This strategy envisages that the Ministry of Health and includes Icelandic targets for healthcare Iceland should become the issues such as the use of IT in until 2010, including tools to leading nation in electronic healthcare, data security and storage as measure the effectiveness of services including in the well as the use of standards. healthcare services field of healthcare.

Figure 3: Icelandic Policy documents related to eHealth

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3.2 Administrative and organisational structure²¹

Iceland has a centralised health and medical care system. Thereby, the financial responsibility lies on the Government but the responsibility for operating the different hospitals and health centres is delegated to the respective boards. The role of the Government is also to provide the legal framework and supervising that medical care is safe, of good quality and equitably distributed. Furthermore, the government's informatics policy defines the evolution of electronic healthcare and social settings.

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²¹ Landlæknisembættið ; Ministry of Health ; Prime Minister's Office 2004; European Commission 2007



The Ministry of Health is responsible for the overall administration of health affairs and matters relating to health insurance. Promotion of Information Technology in the health services in Iceland is among the issues that the Ministry deals with. The Ministry is also the coordinator for projects in the Healthnet programme.

Another institution is the State Social Security Institute of Iceland (SSSI), as it introduces electronic services in healthcare. It monitors the main database, which contains health and public related information. The data collection is essential for the structure, storage and retrieval of patient data.

The important functions of the Directorate of Health in Iceland include the monitoring and assessment of different initiatives and databases as well as international and European collaboration – for example, the participation in the European Network for Health Technology Assessment²² (EUnetHTA). Generally, the Health Directorate of Health is a government agency headed by the Medical Director of Health. Its five divisions are responsible for administration, public health and clinical quality, infectious disease control, health statistics, and finance.

Also responsible for administrative and organisational tasks in healthcare IT is the Public Health Institute, which was officially established in 2003. It is mainly responsible for communicating significant changes to the public by reinforcing knowledge through research and teaching, educating in cooperation with relevant partners and functioning as an advisor to the government.

3.3 Deployment of eHealth applications

3.3.1 Patient summary and electronic health record (EHR)

In this study, the epSOS project's definition²³ of a patient summary was used as a general guideline. There a patient summary is defined as a minimum set of a patient's data which would provide a health professional with essential information needed in case of unexpected or unscheduled care (e.g. emergency, accident), but also in case of planned care (e.g. after a relocation, cross-organisational care path).

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

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²² EUnetHTA

²³ European Patients Smart Open Services



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.

On December 17, 1998 the Icelandic Parliament adopted an Act on a Health Sector database, Act no. 139/1998, which provides a legal framework for the operation of a centralised database containing non-personally identifiable health data from medical records stored at health institutions and at the premises of self-employed physicians. The minister of Health and Social Security introduced the bill in the spring of 1998. The bill led to a widespread public debate with the participation of health professionals, scientists, and other interested parties. Finally the bill, with numerous alterations of which many where made under the parliamentary process, was passed by the Parliament with an almost two-third majority of the votes after an unusually extensive public debate in Iceland.²⁴

Five years after this decision, the Icelandic database was shelved as the court judged the privacy of citizens to be in peril. Iceland's Supreme Court ruled that the transfer of a dead patient's health data to a proposed genetic database would infringe the privacy rights of the man's descendants. The ruling casted further doubt over the nation's plans for a Health Sector Database to hold centralised electronic health records on its population. Furthermore, the company contracted to build the database — deCODE Genetics of Reykjavik²⁵ —already postponed its development. The plans were quietly put on ice in 2002 after the company was unable to reach agreements with regulators about what information the database would contain or with hospitals about who would pay for it.²⁶

Icelandic Healthnet system for electronic communication

Today, the Icelandic Healthnet provides the services needed for electronic communication in healthcare. It was planned and piloted between 2000 and 2006 and is operational since 2007. It provides the following services:

- connection to all institutions related to Healthcare;
- proper bandwidth for various communications;
- open standards;
- secure connections and communications.

Thereby, it connects the following stakeholders in the healthcare system:

Healthnet connection between the following stakeholders:

²⁴ Arnardottir, Björgvinsson et al. 1999

²⁵ deCODE genetics

²⁶ Abbott 13/03/2004



- Pharmacies
- General practitioner
- Hospitals
- Specialists
- Healthcare Centres
- Icelandic Medicines Control Agency
- Ministry of Health
- General Directorate of Health
- Institute of Social Security

The network is managed by a board, which consists of the Ministry of Health and Social Security, the General Directorate of Health, the Institute of Social Security, regional hospitals, health clinics, the Icelandic Medical Association and the Nurse Association as well as the Icelandic Software company association ICEPRO (electronic commerce). The establishment and further development of Healthnet is part of the National Health Plan, which is described in section 4.1.1.²⁷

Furthermore, Healthnet is operating as a communication framework for the electronic health record system (Saga system). All healthcare centres use the same software, and efforts have been made to harmonise electronic records in hospitals and healthcare centres.²⁸ The Ministry of Health and Social Security published minimum datasets for electronic health record (EHR) systems and communication between systems already in 2001²⁹. The harmonisation enables the integration of information and efficient coordination among centres. Thereby, mostly primary care patient information, laboratory tests and surgery data are sent and Picture Archiving and Communications Systems (PACS) and Radiology Information Systems (RIS) are used.³⁰

Figure 4 summarises the developments of data storage and health record development in Iceland:

Figure 4: Patient summary in Iceland

-

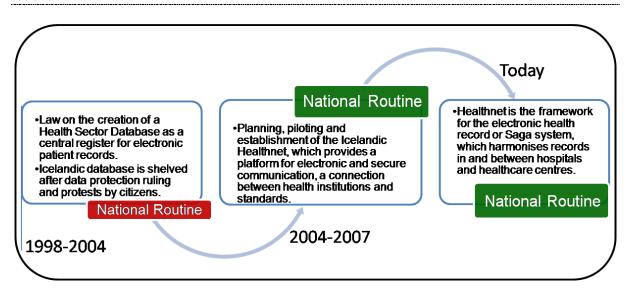
²⁷ Einarsson 2004

²⁸ World Health Organisation 2003

²⁹ European Commission 2007

³⁰ European Commission 2007





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3.3.2 ePrescription³¹

In the framework of this study and following work in epSOS, 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.

Iceland has a national ePrescription system, is based on one technical solution and it has the approval of the Data Protection Ombudsman. Doctors enter the prescription through a portal which is part of the national Healthnet framework. All healthcare facilities are connected to a single administrative entity and make use of special data sets for accessing the system. This register also allows transmitting prescriptions to pharmacies. In general it covers all prescribed medicines that can be purchased in pharmacies irrespective of its reimbursement status. It is managed by the Directorate of Health (for further information on the Directorate see section 3.2).

The experimental phase (with the participation of healthcare centers, a local hospital and few pharmacies) ended in 2007. By the end of autumn 2008, all primary healthcare (centres, local hospitals) and the majority of pharmacies were connected. In the beginning of 2009 the project entered its final phase, with the Landspitalin University Hospital, specialists and the last 3 pharmacies joining the network. In order to ensure security and avoid misuse, eID is used together with other safeguards.³²

Information, which is available in register, is the following:

Icelandic Prescription Register encompasses the following data:

-

³¹ Andersson 2009

³² Hämäläinen and Doupi 2008



Dispensed drug:

Identity: ATC, Nordic product number, etc.

Amount: DDD, number of packages, etc.

Price: total, patient cost, reimbursed cost

Patient information:

PIN

Place of residence

Prescriber:

Profession and specialty

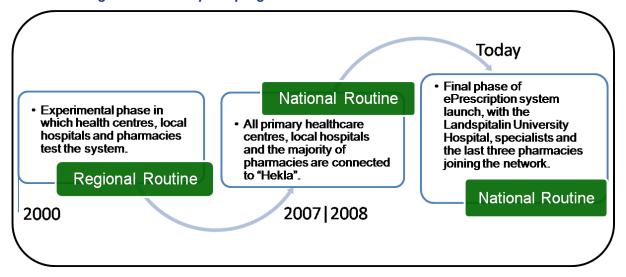
Dosage

In addition, the register is used to control prescribers and patients as well as for statistical purposes. Up to this point, not all nursing homes are covered by the register.

Before the prescription database was established, electronic prescription pilots were already in place for several years. Until the system was operational, prescriptions were sent to pharmacies by GPs and health units on a regional level since the year 2000.

Figure 5 summaries the ePrescription progress in Iceland:

Figure 5: ePrescription progress in Iceland



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3.3.3 Standards³³

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,

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³³ European Commission 2007



Directorate of Health is responsible for healthcare coding and classification standards related to the domain of health informatics, such as the SNOMED Clinical Terms or the LOINC terminology.

In Iceland, the Directorate of Health is responsible for the translation and updates of healthcare coding and classification systems in the country. Hence the Directorate makes the decision on which coding and classification systems are to be used for clinical documentation in healthcare as a government agency. This office is furthermore an adviser to the minister and the government on all health issues.

Besides the Directorate of Health, the Ministry of Health collects health information based on codes on a regular basis.

On a national level DICOM is the current standard for digital medical images, BS 7799 is the currently used standard for information security management and HL7 for healthcare data interchange.

In addition, ICD-10 and ICD-O are used to code medical diagnosis, NCSP and NCSP+ for surgery procedures, NANDA for nursing diagnoses, NIC for nursing interventions, ICPC for reason for visits in primary healthcare, ATC for medication, SRTG for X-ray ordering and results, SNOMED CT for pathology, and LOINC for laboratory ordering and results in primary healthcare.

3.3.4 Telemedicine³⁴

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"³⁵. 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 delivery³⁶.

The first telemedicine project in Iceland started in 1993 with the sending of X-ray pictures from a small hospital in the Westman Islands off the south coast to the Landspítali University Hospital. Since then, six hospitals have been connected to Landspítali in Reykjavík and Akureyri Hospital in the north. Through different projects during the last years new applications and services were and still are constantly developed. The projects include teleradiology, teleobstetrics, telepsychiatry, maritime telemedicine, telemedicine in surgery, telepathology and projects for the use of telemedicine in various consultations. These are also processed through cross-border cooperation, as for example the University Hospitals of Iceland is a member of the Nordic Telemedicine Association³⁷. At the moment, the overall goal related to telemedicine is to create a comprehensive communication platform through the Healthnet system.

Telemedicine projects since 1993 and an ongoing development

³⁴ IST World; Halldorsson 2003

³⁵ Europe's Information Society

³⁶ European Commission 2008

³⁷ Nordic Telemedicine Association



Important regional projects that enhanced the use of telemedicine are the following (small selection):³⁶

- Telepsychiatry: Videoconferencing equipment was used between the University Hospital Landspitali and two health centres to provide psychiatric consultation and interviews with healthcare staff and also directly from doctor to patient. In addition, telemedicine was used in specialist visits to the health centres. The project was successful and showed the need for such a service in rural areas. Further use of the service is under discussion. The project was running from 1997 through 2000.
- The PICNIC (<u>Professionals and Citizens Network for Integrated Care</u>) project, in which the Icelandic University Hospital (Landspítali) participated from 2000 to 2002, developed scenarios on new forms of patient-centred delivery of care in close cooperation with industry.
- Telepathology: Pathology is seen as a highly specialised medical field in which the interpretation of tissue sample images requires a trained specialist, a high-quality microscope, a method allowing presentation of the images using a microscope, and display technology for tissue samples on glass slides. In Iceland, high-quality cameras were installed on the microscope to digitise the image for transmission. The University Hospital of Iceland has used this setup for sub-specialist consultations abroad (with the Armed Forces Institute of Pathology, AFIP, in Boston) using web-based communications.

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 Iceland and for which purpose.

3.4.1 Unique identification of patients³⁸

In Iceland, persons are identified with a unique identification number. The ID-number is a 10-digit number (kennitala), through which citizens are identified in the National Register of Persons. The ID-numbers are issued at birth to all children born in Iceland and at first registration to all persons that take up domicile in the country. This ID-number system exists since 1952 and is the only universal one used in the country.

For further use of the ID-number system in terms of giving citizens electronic access to their data, a working group charged with the task of proposing a public key infrastructure (PKI) for the Icelandic government delivered its findings to the Minister of Finance in November 2001. It suggested connecting the PKI structure to a smart card, as it is done e.g. in Norway or Sweden.

The National Registry; The Government of Iceland's Committee on PKI 2001; European Communities 2009; Graux, Inte et al. 2009



Ongoing development of eIDs in connection with smart cards for multiple purposes

In addition to this planning, the ICT strategy from 2008 "Iceland the e-Nation" is aiming for the development of eIDs for all citizens. Originally, it was the Government's objective that every citizen should have an electronic ID on a smart card by 2008. At this point, the project work is ongoing together with the Icelandic banks: The goal is to build up an open and standardised environment for eIDs, compliant to the European standards, and at the same time, ensure that the content fulfils the requirements of both partners. The bank's plan was to renew all the debit cards in the country in 2009, so that the cards arrive quickly in the hands of all citizens.

At present, electronic authentication for most governmental applications is primarily based on username and password combinations, and only a few services for citizens use and support digital certificates (none of these, though, in the field of eHealth). Distribution of bank cards with certificates has begun, but it is expected that wide-spread coverage will be realised in about two years time.

Generally, the eIDs will be used for government services where authentication and digital signature is required. It is also expected that the eIDs will be used to access the home banks which are used by more than 70 % of all Icelandic citizens.

3.4.2 Unique identification of healthcare professionals

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

Licensed medical professions:

Medical Doctor, Dentist, Pharmacist, Registered Nurse, Midwife, Medical Laboratory Technologist, Physiotherapist, Occupational Therapist, Development Therapist, Social Worker, Licensed Practical Nurse, Optician, Pharmaceutical Assistant, Radiological Technologist, Massage Therapist, Emergency Medical Technical, Nutritionist, Dietician, Food scientist, Diet Cook, Food Technician, Medical Secretary, Dental Hygienist, Dental Assistant, Podiatrist, Speech Therapist, Biologist in a Specialised Health Institution and Chiropractor.

Thereby, the Directorate of Health is the competent authority to issue these medical qualifications (according to Act. no. 12/2008). In 2006, a pilot for the implementation of digital IDs for healthcare workers started and is still ongoing.

3.5 Legal and regulatory facilitators³⁹

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.

³⁹ Icelandic Data Protection Authority; European Commission 2007



The security of information and the protection of personal privacy are guiding principles for Iceland's information society development. Applications in the field of eHealth are directly affected by legislation in the various fields of organising the health system and legislation on data protection. Furthermore, the discussion on the Health Sector Database led to updates of data protection and processing.

The Health Sector Database, which was shelved by a ruling on an individual case (see section 3.3.1) in 2003, was criticised for the fact that citizens were identifiable both in the preparation of data for transfer, in the opt-out database and in the Health Sector Database. Therefore, the prior consent of the patient is now required to be part of any database, in which health data on individuals are permanently retained for research purposes.

Act on the Protection and Processing of Personal Data

On 1 January 2001 the Act on the Protection and Processing of Personal Data, No. 77/2000, entered into force. This Act aimed to implement Directive 95/46/EC into Icelandic law and applies to any electronic processing of personal data. It gives the Icelandic Data Protection Authority the responsibility to monitor the applications of data protection regulations. The act was updated in 2003 – changes predominantly were focused on the electronic surveillance of citizen, which includes health issues.

The Data Protection Authority exercises surveillance over processing of data to which the act applies. The authority mainly deals with specific cases on the basis of inquiries from public authorities or private individuals, or cases taken up by the Authority on its own initiative. The Act also requires that the opinion of the Data Protection Authority must be obtained prior to passing new laws, orders and regulations concerning the protection of privacy.

Act on electronic signatures

Regarding electronic signatures, an Act in 2001 included the legal requirements set by the European Parliament and Council Directive (1999/93/EB) on a Community framework for electronic signatures. The aim of the Directive was to harmonise the rules within the Alliance on the use of electronic signatures in light of the increased volume of electronic trading. The law defines the legality of electronic signatures, and the requirements for certificates, signature creation devices and certification service providers.

In 2003, the Icelandic Parliament passed a bill on the prescription database (see also section 3.3.2), permitting the State Health Insurance Organisation to register data from all doctors' prescriptions of medicines. The purpose of creating such a database is to prevent abuse of prescription drugs and to give an overview of the nation's drug consumption. Access to personal data is controlled by the Director of Public Health. As a result of the opposition to the draft bill by the Data Protection Authority, the bill was modified to implement encryption means to protect the personal data.

3.5.1 Patient rights⁴⁰

In 1997, Iceland passed a law on patient rights ("Act on the Rights of Patients"), which is aiming to ensure that there is no discrimination against patients on grounds of gender,

lcelandic Government; Ministry of Health 1997, Revised translation 23.08.09; Icelandic Government 2000, Translation 2007; Arnason 2002



religion, beliefs, nationality, race, skin colour, financial status, family relation or status in other respect. This act was amended in May 2009 (Act no. 55/2009), which had the purpose to regulate the handling of electronic medical records in terms of patient and professional access and data protection. The following box outlines which patient rights it defines:

Patient rights in Act 55/2009:

- Patients have access to their medical record
- Patients can hide certain information in their record
- Healthcare workers have to inform the patient before they access a medical record
- In case of a patient's death no information about his/her health record is given to third persons exceptions are close relatives who provide a profound reason
- Health data is distributed by the Directorate of Health for research purposes if the patient agrees

In addition – according to the Patient Rights Act – patients have the right to obtain information regarding: their state of health, including medical information on their condition and prognosis and the proposed treatment, as well as information on its course, risks and benefits. A patient can appoint another person to receive the information in his/her place. It is entered in the clinical record if the patient declines information on his/her health and prognosis or appoints another person as representative. The identity of the person receiving the information is also documented.

3.6 Financing and reimbursement issues⁴¹

The financial responsibility for healthcare in general lies with the Government but the responsibility for operating the different hospitals and health centres is delegated to the respective boards.

Tax-based healthcare system

In detail, 85% of healthcare is funded through taxation. The portion of the healthcare services that are not tax financed, i.e. 15 % of the total, is almost exclusively comprised of direct household payments, the largest part being private payment for specialist consultations, ambulatory operations and dental care, as well as co-payments for pharmaceuticals. Iceland spends a high percentage of its national budget on healthcare. In 2007 total healthcare expenditure as a proportion of GDP was 9.3%, this figure ranging well above the EU average of 8.7%. Furthermore, private health insurance hardly exists in Iceland and health services provided by employers are very limited.

The funding for implementation of eHealth systems and applications is mostly for pilot projects (percentage of total cost, hardware, software etc.) from state to healthcare

⁴¹ Heilsunet; Ministry of Health; Halldorsson 2003; World Health Organisation 2006; European Commission 2007



organisations. And eHealth services are reimbursed mostly according to contracts between the providing and receiving parties of the services.

In sum, funding for the building of an ICT infrastructure in healthcare, the "Heilsunet project" remains challenging, as it is difficult to secure financial support. This is being addressed by sending contributions directly to projects and re-allocating funds within institutions more appropriately.

3.7 Evaluation results/plans/activities⁴²

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 Iceland, evaluation activities are still rather infrequent, but some smaller assessment activities – especially in telemedicine – can be observed:

During 2004, the Ministry of Health and Social Security sponsored a survey focusing on the possibilities for people suffering from handicaps to use information technology in their communications with the healthcare system.

Evaluations of telemedicine projects have been made, as the following examples show:

- (1) <u>Desktop video-conferencing</u> equipment was installed in university hospitals and a health centre for a trial to use specialty support for fetal ultrasound examinations. An evaluation of the project was carried out in 2001.
- (2) Teleobstetrics using the Healthnet: A special user interface was made for the desktop video-conferencing equipment already installed. The participants were the university hospitals and a health centre. By modifying the user interface (decreasing the numbers of buttons and icons and emphasizing important functions on the screen), doctors and midwives could rapidly learn how to use video-conferencing for consultations. The evaluation was performed by a web-based form. Communication was made by two-Mb/s ATM connection, using Ethernet. The project ran from 2001 through 2003.
- (3) A Project for the <u>use of telemedicine in different consultations and specialities</u> by Icelandic research council from 2003 through 2005 was performed. Here, the evaluation was carried out by web-based forms filled out after each consultation by the general practitioners and specialists concerned. Forms on paper are available for the patients. In each phase, doctors evaluate the organisational matters. The lessons learned from the project are planned to be used in establishing Guidelines for Telemedicine services in Iceland (see section 3.3.4).

⁴² Ministry of Health 1997, Revised translation 23.08.09; Palsson and Valdimarsdottir 2004



4 Outlook

Iceland pursues an integrative approach towards healthcare technology, which leads to different overarching databases for electronic communication, data storage and connection between healthcare providers. The most prominent system, the Health Sector Database, was widely discussed in parliament, court and in public and was then shelved in 2002. Over 20 000 patient opted out of the system in fear of data misuse. But overall, this did not harm the development of health informatics in Iceland.

Today, the Healthnet (Heilsunet) provides the services needed for electronic communication in healthcare and poses the framework for the Saga system, which enables the transfer of electronic health records. Furthermore, Iceland has a prescription database that is essential for the daily medication routine of GPs and hospitals as well as for medication records and drug surveillance. Regarding these systems, Iceland has learned a lesson from the Health Sector Database case and updated its legislation on data protection, patient rights and (electronic) identification.

In sum it can be stated that through early regional projects, healthcare technology structures were developed up to a national level. And it seems that people, although many opted out of the previous database, did not lose their confidence in electronic systems and still use eServices in healthcare. Having a considerable part of the main infrastructure components in place, and already in good progress with regard to eHealth applications implementation, Iceland will need to focus more on ensuring the financing of eHealth in the future and developing added value eHealth services for citizens and professionals.



5 List of abbreviations

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

EUnetHTA European Network for Health Technology Assessment

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

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

OECD Organisation for Economic Co-operation and Development

PHS Personal Health System

R&D Research and Development

SNOMED Systematized Nomenclature of Medicine-Clinical Terms

SSB Social Security Board

SSSI State Social Security Institute

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) 	
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 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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