



# Final project report

## Deliverable 5.3 in the framework of the eHealth ERA project

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### eHealth ERA

Towards the Establishment of a  
European e-Health Research Area

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## Executive Summary

This final report concentrates on describing the ten official final outputs of the eHealth ERA coordination action. Yet it also points to the many additional activities of the project requested by either the European Commission or the Member States, and also both together, which brought fruit to a wider understanding of eHealth in Europe. The project – just as has the development of the whole notion of a European eHealth Area – had a high public profile.

Starting before the project's foundation, the report charts the history of eHealth in Europe, and the development of the European Union Member States' policies in this field. The report then outlines step-by-step the aims and goals of the eHealth ERA project and how it was formed and has grown since its initiation.

In terms of the development of theory and research methodology, the notion of an eHealth framework is outlined, as are the other methodological tools developed within the parameters of the project. The principal focus of the report is, however, on the project's key deliverables. These include the overview of 32 countries' eHealth policies and strategies; the way in which the project was able to develop an intellectual focus on the importance of both the patient summary and patient empowerment for European eHealth; and the importance of undertaking a strengths, weaknesses, opportunities and threats analysis so as to enable focus on the core issues involved in these two areas of potentially high-concentration activity. While the report first emphasises the role of policy in eHealth, it later outlines some important and groundbreaking, new findings into eHealth research in Europe. Since process and an awareness of publicity is always important in European Union-financed projects, but especially in coordination actions, the report also examines what the project has achieved by way of disseminating and making known its findings to a wider public.

Now the greatest challenge for European policy-makers is to assess what are the prospective outlooks for the future in terms of both research policy, and implementation and deployment policy (entrepreneurial and/or enterprise policy have not been topics of this initiative). Hence, the concentration is now two-fold: the analysis provided looks at, from the research perspective, eHealth as an accumulating science and, from the deployment focus, eHealth as a means of supporting and serving safe, high-quality, and efficient healthcare. Progressive new directions are suggested to be in the domains of further joining together, working together, and measuring together. Additional factors are raised that relate to process, procurement, publicity-making and partnership-building, as well as efforts related to measuring empirically progress in eHealth through the development of eHealth indicators.

Europe now needs a vastly improved healthcare communication space that enables all the relevant actors not only to exchange and to share information, but also to collaborate on providing a better health service to each individual European citizen. It is hoped that the work of the European eHealth ERA project has helped shift public and policy understanding in this direction, and that it – and any successor activities – can further strengthen the benefits that will occur through bringing health and ehealth together: the latter firmly supporting the former.

# 1 Introduction

Every social development reaches a crucial turning-point. This was the case of eHealth in Europe in 2005. Not only had RTD in the field come to a stage where many of its forty-year developments were now about to be taken up in a highly practical way in Europe, but Europe's nations were now keen to seek solutions to the many pressing health challenges facing them individually and communally. So too, came a renewed need to explore more innovative and challenging technologies, through targeted research, that may help to enhance European's health.

These kinds of initiatives at the level of an entire continent do not happen on their own. They require policy support – from health policy, from ICT research policy, and from policies on implementation and deployment. So, it was in the middle of the first decade of the twenty-first century that the notion of the European Research Area (ERA) came about. Not only could an ERA be conceived that would support basic research, but an ERA could also support innovation-oriented and implementation-oriented research. Not only could there be a single ERA, but there could be ERAs devoted to different research topics and fields.

This breadth of thinking is certainly the case of the coordination action for the eHealth ERA. It puts forward a vision of an unprecedented and exciting use of ICT that ensures good, accessible, quality, safe, and secure healthcare for Europe's citizens while it also suggests a concept that can facilitate a much more successful, leading new industrial domain for Europe and, in parallel, outline new research drivers for the European eHealth scene..

This report reviews not only the underlying context to the foundation and development of the eHealth ERA coordination action, but also how it survived, and even thrived. It examines step-by-step the coordination action's core achievements in scoping the European eHealth landscape. It covers what is happening in thirty-two of the European countries, and where those countries' strategies and priorities have brought them collectively. It reiterates the key findings of the two areas of work requested by the Member States – on patient summaries and on patient empowerment. Those two areas of concern can, and have, however, been combined into a single lens, a coordinated view of next steps: this strengths, weaknesses, opportunities, and threats (SWOT) analysis is explained in this final report in detail. The concentration on work in the eHealth implementation and deployment sector is also integrated with a comprehensive and insightful view of the status of eHealth RTD in the Union today, and its possibilities for a more coordinated and structured RTD approach in the future. Finally, these insights are summarised in a short overview of key findings geared towards the needs of European policy-makers.

It is these findings that bring European policy-makers to another key juncture in decision-making. It presents a key period of thinking about how to organise health systems and their supporting eHealth RTD and implementation/deployment actions. How can these core fields of eHealth activity – RTD and deployment/implementation – be handled in a unified and coherent way when – at least today – the responsibilities for them are distributed throughout many different bodies, many different organisations, and many entities with very different viewpoints?

## 1.1 Charting eHealth in Europe

As argued elsewhere, the health systems of the European Union (EU or Union) are a “fundamental part of Europe's social infrastructure”<sup>1</sup>. The challenges that lie ahead consist of reconciling individual health needs with the available finances, as the population of Europe ages, expectations rise, and medicine advances.

While healthcare expenditure is expected to continue to increase, the scope for increase of the financial resources to meet this demand is limited. Yet, the scope for an increase in citizen and consumer demand for more, better, safer, and timelier healthcare is unlimited. As a consequence, given budgetary constraints, healthcare systems face the critical challenge of optimising the use of resources in order to meet this growing demand on the part of citizens and patients. An associated challenge is to use existing and emerging technologies to optimum effect, even when this means changing established and long-valued working and clinical practices.

Information and telecommunication technology (ICT)-based solutions in health (loosely defined as eHealth, a term to which we will return in Chapter 2) can be used today in a highly beneficial way in healthcare. They can be used to address those key challenges that are faced by European healthcare systems. ICT-enabled solutions to support the implementation of improved and new models of healthcare are an old dream, that was first conceived and discussed some 40 years ago, but was never successfully implemented on a larger scale<sup>2</sup>. Now technical advances, and pressing needs to cope with ever-increasing demands on healthcare systems, have led to a renewed interest in these applications. Similarly, for almost 20 years now, the EU has supported technology-focused research in this field.

It is anticipated that the second half of the first decade of the new millennium will see large-scale implementations of eHealth solutions. These are instigated and stimulated, at least in part, by the EU eHealth action plan, embedded as it is in the wider context of achieving the goals of the Lisbon Strategy through its subsequent EU and Member State activities. The creation of a European eHealth area<sup>3</sup>, ease of patient and health professional mobility<sup>4</sup> and empowerment of the citizen through eHealth tools and services<sup>5</sup> have become key policy objectives of the Union.

All of this requires a vastly improved healthcare communication space that enables all the relevant actors not only to exchange and to share information, but also to collaborate on

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<sup>1</sup> Adaptation of introductory text from Deliverable 1.1, *Conceptual framework for eHealth Interoperability*, re-submitted May 2007, Semantic Health.

<sup>2</sup> Ed Hammond, the “grandfather” of eHealth in the USA, started already in 1967 to programme his first version of an electronic health record. In Germany, in the early 1970s, a huge project called DOMINIK was based on mainframe computers, but it failed dismally. The early dreams of global satellite-based telemedicine networks developed at the same time-period never became reality beyond the military and research environments.

<sup>3</sup> COM (2004) 356, e-Health - making health care better for European citizens: An action plan for a European e-Health Area, Brussels, 30.04.2004.

<sup>4</sup> COM (2004) 301, Follow-up to the high level reflection process on patient mobility and health care developments in the European Union. Brussels, 20.04.2004.

<sup>5</sup> This was the overriding topic of the 2004 European high-level eHealth conference in Cork, Ireland, in May 2004. Cf. Wilson, P., Leitner, Ch. and Moussalli, A. (2004): *Mapping the Potential of eHealth, Empowering the citizen through eHealth tools and services*. Maastricht: European Institute of Public Administration.

providing a better health service to each individual citizen. This cannot be achieved without multi-level interoperability of the developing applications, systems and infrastructures.

## **1.2 Highlighting eHealth ERA aims and goals**

The eHealth ERA coordination action has aimed to contribute to establishing an effective European Research and Innovation Area (ER[IA]) in this particularly important European Information Society Technologies (IST) research field and market. Reducing the disparity of current eHealth planning can be expected to have a strategic impact on regional, national and trans-European eHealth infrastructures, improve the quality of medical outcomes, and enhance the quality of life for citizens in the Union.

The goals of the eHealth ERA coordination action were fourfold:

- to support Member States' eHealth strategy development
- to support implementation-oriented eHealth research and technological development (RTD)
- to identify opportunities for multilateral joint eHealth activities; and
- to attempt to indicate the initial steps that need to be taken towards further integration of eHealth deployment and implementation across European countries.

A consortium of five research management bodies - coordinated by empirica at the request of the German Federal Ministry of Health and Social Security (BMGS) committed itself to undertaking a specific group of tasks. These were to research and structure European eHealth strategies and RTD; identify priority topic clusters; locate cooperation opportunities; propose priorities for action; build a suitable eHealth ERA website and undertake appropriate dissemination activities. A Coordination Committee, composed of the i2010 subgroup on eHealth, of which representatives from 29 health ministries are members, oversaw and directed the work, and facilitated decisions on the initiative's priorities. Towards the project's end, the individual Member States collated their respective eHealth roadmaps, decided on two key priorities for action (patient summaries and patient empowerment); and – in parallel – initiated a mutual engagement in joint eHealth implementation activities.

Now under current discussion are what are the necessary mechanisms that would need to be adopted to ensure the initiative's continuity. The project's key observations and conclusions are therefore of considerable importance in supporting that discussion.

Overall, it was foreseen that the coordination action would enable the Member States to achieve greater transparency and provide public availability of information about their eHealth activities; address more effectively the current fragmentation of the European eHealth RTD and eHealth implementation/deployment landscapes; help to counter the poor take-up record to date of eHealth RTD; make a major contribution to future European eHealth RTD in the IST Programme; and enable policy-makers to gain insight into possible future directions in both the eHealth RTD and implementation/deployment fields. This report helps to make that assessment with regard to the coordination action's achievements.

### **1.3 Charting the background to EU and Member States' eHealth policies**

A brief overview of the way in which European and Member State eHealth policies have developed since the formation of the EU is useful. It has been widely argued that, even in the mid- and late decades of the second half of the twentieth-century, the early visions of eHealth bore little fruit.

Certainly, a shift is now occurring that brings eHealth from purely a vision of how health services could be provided to an everyday reality or, at least, a reality that could now more certainly be on the verge of materialising. Today, there is a renaissance of interest in the eHealth area. The core focus of this visions is on the connectedness or interoperability of health systems and services in Europe.

A number of eHealth initiatives took off in the early part of the first decade of the twenty-first century, just as this clear re-emergence of eHealth visions took place. These initiatives counterbalance the previous trend in which the healthcare sector was permeated by lobby groups which regulated and/or influenced its activities, and which resulted at least partly in eHealth RTD results and eHealth take-up being relatively poor.

The overall European Research Area (ERA) initiative was launched to facilitate the progress of European RTD. Since its inception, further observations were made that have allowed the creation, enhancement, and sustainability of ERA activities that were to be launched at a later date – including the eHealth ERA initiative.

#### **Early visions bore little fruit**

During the 1960s and 1970s, engineers and medical doctors invested a great deal of time and effort in trying to use various emerging technologies to deliver sophisticated medical services to the most remote areas of the globe, for example, *via* satellite.<sup>7</sup> However, in spite of the great potential, of the technologies on offer, and the often exuberant optimism of its proponents, many prospective projects failed. It was not possible to translate what was at the time referred to as telemedicine into ongoing service provision. In the early 1980s, it was thought that eHealth had failed to live up to its initial promise.

This international failure to exploit RTD in telemedicine was shared by the EU RTD funding programmes. More than fifteen years ago, the Telematics Applications Programme funded research in the health domain with the objective of enabling "the entire healthcare sector to benefit from access to telematics services."<sup>8</sup> What was at that time called health telematics, today equates with eHealth. Support to RTD continued in the Fifth Framework Programme (5FP) in a similar direction. Research in the 5FP was focused on the need to "exploit

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<sup>7</sup> See Hild, Carl M. (2000) *Arctic Telemedicine Project Final Report*. Presented to the Sustainable Development Working Group of the Arctic Council. Institute of Circumpolar Health Studies (ICHS), University of Alaska Anchorage, August 2000, pp. 82-83.

<sup>8</sup> European Commission, IS Directorate (2001): 4th Research & Development Framework Programme (1994-1998), *Healthcare Telematics Projects. Final Report*, Brussels, Nov. 2001

seamless connectivity and interoperability of information infrastructures" in health.<sup>9</sup> However, in spite of considerable RTD support, healthcare providers still face notable challenges to the interconnectivity and interoperability of healthcare systems.

Even in the recent past, the conditions for the exploitation of RTD results were simply either not known or available. As a result, eHealth RTD has continued to be regarded with scepticism by many practicing healthcare professionals. It is these healthcare occupations which have seen RTD projects fail to meet the requirements of routine service application – despite the dedicated involvement of user groups and medical institutions. As a consequence, eHealth's benefits were for over a decade lost to Europe's healthcare systems.

### **A renaissance of interest**

Despite the relative failure of some of the more ambitious RTD initiatives worldwide, a range of ICT infrastructures and applications has been gaining ground internationally although this is taking place more slowly than in many other commercial or industrial sectors. Based on this contemporary reality, an awareness of eHealth infrastructures and applications have been constantly gaining ground at the European level. eHealth is now seen as a key means of enabling health systems to cope with the mounting health and social care challenges that are spread across the EU.<sup>10</sup>

### **Infrastructure challenges**

A key hurdle for the further development and diffusion of advanced telemedicine and eHealth inventions and innovations across Europe remains the inadequacy of infrastructures available at both national and local levels in the various Member States of the EU. When they are available, these infrastructures are characterised by a widespread lack of interconnection and interoperation; a multiplicity of legacy task-specific information systems; stand-alone systems for what are actually related administrative tasks; and a preponderance of mainframes that use proprietary software rather than client-server, or other, networked platforms and that support standards-based or open source software. These characteristics of the ICT infrastructure in healthcare are compounded by the security and privacy issues that are typical of the health sector, the impact of which is aggravated by a lack of commonly agreed, adequate, and applied medical and clinical standards.

### **New initiatives underway and a re-emergence of vision**

As a result of the renewed interest in eHealth and in recognition of these problems both at the national and at the European Union level, various RTD activities to assure the interoperability of eHealth systems and establish relevant technical and medical/documentation standards are underway or planned<sup>11 12</sup>. These activities will support

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<sup>9</sup> European Commission, IS Directorate (2003): *Applications relating to health, Fifth Research & Development Framework Programme 1998-2002. Final Report*, Luxembourg, April 2003

<sup>10</sup> Public consultation on health services by the DG Health and Consumer Affairs. *Developing Community Framework for Safe, High Quality and Efficient Health Services*. [http://ec.europa.eu/health/ph\\_media/co\\_operation/mobility](http://ec.europa.eu/health/ph_media/co_operation/mobility)

<sup>11</sup> See TMA Bridge final report. <http://esamultimedia.esa.int/>

<sup>12</sup> Draft Revised Document in preparation of Draft Recommendation of the Commission on eHealth Interoperability. 16.7.2007: [http://ec.europa.eu/information\\_society/newsroom/cf/itemlongdetail.cfm?item\\_id=3540](http://ec.europa.eu/information_society/newsroom/cf/itemlongdetail.cfm?item_id=3540)

the advancement of national health and social care systems, the creation of a seamless pan-European healthcare market, the further growth of the European health ICT industry, and the sustainability of its international competitive advantage. At the same time there is again growing enthusiasm for more widespread exploitation of recent developments in ICT, with a re-emergence of eHealth visions.

In conjunction with these developments, in April 2004 the EC published a Communication entitled *eHealth - making health care better for European citizens: An action plan for a European eHealth Area*.<sup>13</sup> Based on a concise analysis of past achievements, the present situation and future needs in the fields of RTD, and applications and implementations across all the Union's Member States, a detailed three-page roadmap was developed to guide future eHealth activities that extend throughout the seven-year period from 2004 to 2010.

### **The need for EU level coordination**

According to a 2004 report by the IST Advisory Group (ISTAG),<sup>14</sup> much effort was placed over the previous ten-year period on "developing systems that would enable eHealth to operate across borders at EU level, and many different pilot initiatives have been run to demonstrate these in operation. However, eHealth systems have not been sufficiently established at national level, resulting in the lack of eHealth ambitious initiatives in most of the EU countries. There are some exceptions, notably Slovenia and Germany where eHealth cards are being considered. The legacy is also extremely high in this sector, with patients records held in many different manual formats across the EU. Standardising and automating these is an issue that can only be addressed at an EU level, with agreements of all national governments."

### **The healthcare sector is regulated and influenced by a wide range of lobby groups .... and the result is that eHealth take-up has tended to be poor**

The health sector is quite different from many other economic sectors in the Member States in at least the following ways. The domain is highly regulated; it is usually not open to free competition; it is confronted with various legal, regulatory and ethical issues; and it is confined by local, regional or national boundaries and jurisdictions. In addition, many if not most health systems are under the powerful influence of strong lobby groups and organisations that represent but are not limited to various occupational and industrial sectors including healthcare professionals; public, not-for-profit, or private care providers; pharmaceutical, medical equipment and other industries; insurance companies or agencies; and patient and citizen groups.

The influence of these stakeholders has surely contributed to the fact that considerable investment by the EU in eHealth RTD in previous Framework Programmes failed to succeed in its originally anticipated return on investment. The funded RTD initiatives have completed the innovation cycle in all but a handful of cases. At least until 2004, RTD in eHealth was unfortunately one of the poorest performers in terms of the actual exploitation of research

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<sup>13</sup> COM (2004) 356, *e-Health - making health care better for European citizens: An action plan for a European e-Health Area*, Brussels, 30.04.2004.

<sup>14</sup> IST Advisory Group (2004) *Europe Wide Initiatives Building critical mass in cross-border innovation*. ISTAG Working Group [Draft] Report – v6, June 23, 2004, p. 6

results.<sup>15</sup> As a result of such findings, eHealth RTD has in general been funded less intensively than RTD related to a number of other economic sectors that have less overall economic significance.

### The ERA initiative

The European Research Area (ERA) initiative was launched at the Lisbon European Council in March 2000 on the basis of an idea proposed by the Commission some two months earlier.<sup>16</sup> The EU spends only 1.9% of its GDP on research and development, as compared with 2.7% for the USA – a figure which continues to rise – and 3% for Japan. Although Europe accounts for one-third of total world output of scientific publications, it lags behind its competitors in terms of the number of its patent applications, and its trade balance in high-technology products is in deficit. The level of private sector research in Europe is below that of other leading technological nations, and European countries are slower to exploit promising technological markets on a systematic basis. Moreover, more than 80% of EU research is financed at a national level, and benefits from very little overall coordination.<sup>17</sup> The ERA initiative is based on the simple idea that current scientific and technological co-operation activities in Europe are far from sufficient to achieve the targets set.

Against this background, the objectives of the ERA initiative combines three related and complementary concepts:

- the creation of an "internal market" in research, an area of free movement of knowledge, researchers and technology, with the aim of increasing cooperation, stimulating competition and achieving a better allocation of resources
- a restructuring of the European research fabric, in particular by improved coordination of national research activities and policies, which account for most of the research carried out and financed in Europe
- the development of a European research policy which not only addresses the funding of research activities, but also takes account of all relevant aspects of other EU and national policies.

Among the original objectives of this ERA Initiative are two of particular relevance for the eHealth ER(I)A:<sup>18</sup>

- Research and innovation (strengthening technological innovation capacities in the EU, exploitation of research results, ...)
- Science, society and citizen (strengthening the link between research activities and policies and the needs of society).

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<sup>15</sup> *IST Impact Study - Health Domain*, unpublished Draft Final Report by Veli N. Stroetmann et al., empirica and Databank Consulting, July 2004.

<sup>16</sup> COM(2000)612, *Making a reality of the European Research Area: Guidelines for EU research activities (2002-2006)*, Brussels, 1 8.2000, and working document "First report on progress towards the European Research Area", SEC(2001)465 of 16.3.2001.

<sup>17</sup> COM (2002) 499, *More research for Europe: Towards 3% of GDP*, Brussels, 11.9.2002.

<sup>18</sup> CEC, *Making a Reality of the European Research Area*, pp. 6-7

## Creating effective ERA activities

The plan for a general ERA initiative faced a number of barriers which threatened to reduce the impact of the activities undertaken. Thirty months after it was launched, the ERA initiative was reviewed critically in an EC Communication. *The European Research Area: Providing the new momentum. Strengthening - Reorienting - Opening up new perspectives* produced some key principles which were derived in order to sustain the eHealth ERA concept.<sup>19</sup> The Communication's recommendations for overall ERA activities were as follows:

- Assure that a sufficient number of Member States participate
- Clearly identify the RTD area, select subjects of clearly defined action at national level
- Consolidate the conceptual and policy framework in which the project is being implemented
- Provide an environment conducive for stimulating RTD and the exploitation of results;
- Overcome the fragmented nature of activities and the dispersal of resources
- Do not limit activities to exchanges of information
- Incorporate industrial exploitation and the application of RTD results.

This 2002 Communication acknowledged that it is sometimes more difficult to make progress, particularly in terms of exploitation and application of certain research domains, because many different policy areas outside of pure research policy in the narrow sense are involved. Hence, the Communication recommends that ERA actions set up "Coordination Committees", which are composed of representatives from the relevant national authorities, as well as complementary "Working Parties" that consist of experts who are appointed by the Member States. Action on each RTD topic is recommended to be led by one of the participating countries. The document's last observation on incorporating greater industrial involvement was also considered to be a key aspect of achieving the Lisbon Strategy in terms of economic growth and job creation.

In terms of planning the eHealth ERA action, account was duly taken of the recommendations of the 2002 ISTAG working paper which extended the vision of an ERA to that of a "European Research (and Innovation) Area 'ER(I)A'". Indeed, the eHealth ERA coordination action took the insights and conclusions of the ISTAG ERA review paper one step further. It acknowledged explicitly that, if RTD is to contribute to the Lisbon Strategy, it must extend its activities systematically into the exploitation of RTD results by integrating innovation and diffusion considerations. Because of the health field's highly regulated structure, its absence of competition in many fields, and the strong influence that both public policies and public institutions have on its investments and longer-term development strategies, it became particularly relevant to take "account of all relevant aspects of other EU and national policies"<sup>20</sup>.

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<sup>19</sup> COM(2002)565 final. *The European Research Area: Providing the new momentum. Strengthening - Reorienting - Opening up new perspectives*, Brussels, 16.10.2002.

<sup>20</sup> Ibid., p. 4.

## **1.4 Returning to the genesis of the eHealth ERA**

The eHealth ERA coordination action emerged from an initiative that involved more than twenty Member States' health ministries. This originating body of twenty decided to improve coordination among themselves and to exploit the potential for European synergy in eHealth (see Annex 1). These Member States had three expectations: they wanted to overcome or avoid the barriers to patient and professional mobility in the Union; to counterbalance the threat of uncoordinated IST take-up; and to ensure that progress would take place in European Member States in line consistently with the EC's eHealth action plan.

Practically speaking, the German Federal Ministry of Health and Social Security (BMGS) was aware of the objectives of the 6FP IST third call for proposals that was launched in summer 2004. The German health ministry therefore proposed to organise a meeting of Member States' representatives in Brussels. The purpose of the meeting was to discuss possible cooperation mechanisms within the IST Programme in order to support RTD roadmapping and to assure interoperability between different national eHealth initiatives.

After some delay, this meeting took place on 1 September 2004. It was attended by twenty-two Member States' ministerial representatives who confirmed full support for the German ministry's initiative, and decided unanimously to proceed with submitting a proposal to the third call of the IST programme. A team was nominated to lead the activity, and empirica was selected to manage the process and was chosen as project coordinator. A suitable proposal was developed, and underwent the respective evaluation and selection procedures successfully. Following negotiation with the European Commission, a contract was signed. The actual coordination action was therefore launched on 1 April, 2005, shortly before the Tromsø eHealth 2005 conference was held.

## **1.5 Outlining the process of the eHealth ERA**

The whole field of eHealth in Europe has moved ahead by leaps and bounds over the past three-year period, particularly since the launch of the 2004 eHealth action plan. Considerable progress has been made not only as a result of the dedication of the eHealth ERA coordination action but also as a result of the work of a wide range of other projects and initiatives<sup>21</sup>. These developments are laid out in two progress reports on eHealth activities for the years 2005<sup>22</sup> and 2006<sup>23</sup>.

Given the high policy profile of the project and its relatively short time-horizon to accomplish tasks (24 months), in addition to the concrete tasks and deliverables to be accomplished within the initiative, a sound awareness of the lengthy process of group formation has been of considerable importance (Tuckman, 1965)<sup>24</sup>. Two project management issues were of particular importance to the action. They were the requirement not to see undue slippage of deadlines (a considerable challenge given the need to reflect progress throughout the entirety of the 25-Member State, now 27, Union), and the need for precise quality control of

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<sup>21</sup> Examples of projects include Q-REC, RIDE, SHARE, and STEP whereas examples of studies involve eHealth IMPACT, Good eHealth, and Legally eHealth.

<sup>22</sup> Accessed 28 July, 2007.

<sup>23</sup> Currently in draft manuscript; to be published by the Commission Services before end 2007.

<sup>24</sup> Tuckman, Bruce. (1965). Developmental sequence in small groups. *Psychological bulletin*, 63, 384-399.

the various project deliverables. To ensure these requirements were met, the project has experienced three annual technical reviews: the first of which was held particularly early in the project lifecycle so as to ensure a fit with purpose over the whole lifecycle of the initiative. The project has also presented its findings regularly to its Coordination Committee with the aim of receiving constructive criticism and feedback.

### **1.6 Intended outcomes of the eHealth ERA coordination action**

The essential intended outcomes of the coordination action were conceived as being firmly grounded in the perceptions and actions of European decision-makers. It was intended that the coordination action outcomes would include: the improved knowledge of key actors and stakeholders in eHealth in the Member States and at the Union level; enhanced levels of trust and confidence in colleagues in the various ministries, but principally the health ministries, in RTD organisations and stakeholder associations; and a sounder know-how about eHealth policy visions, goals, and decision-making processes.

The intended outcomes of the coordination action, and the dates by which they were expected, are outlined in a simple list in the table below. They are further revisited in chapter 9 of this report with a view to assessing the action's achievements.

Initial and intermediate outputs, with appropriate metrics, include:

- The establishment of a fully functioning Coordination Committee (anticipated month 6)
- The launch of a public eHealth strategies and RTD web site on national eHealth programmes, activities and accomplishments (anticipated month 4)
- The completion of an appropriate conceptual framework and information gathering instruments (anticipated month 7)
- A European eHealth Policy Report, that presents a structured overview of European eHealth initiatives and roadmaps, synthesises topics with priorities common to multiple Member States, and covers information from all Member States and participating countries (anticipated month 20)<sup>26</sup>
- Publication of project knowledge base on the project website (anticipated month 22)
- Coordination Committee decision on priority Topic Clusters (anticipated month 22)
- Report on Topic Cluster One detailing strategic opportunities for joint activities of Member States (anticipated month 22)
- Identification of national institutional structures and connections (from all participating countries)<sup>27</sup> essential to achieve a high degree of cross-Union eHealth innovation-oriented cooperation (anticipated month 25)
- Report on Topic Cluster Two detailing strategic opportunities for joint activities of Member States (anticipated month 23)
- Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis (anticipated month 26)

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<sup>26</sup> To the extent that such information exists and the national authorities submit it.

<sup>27</sup> To the extent that such structures exist and the national authorities submit this information.

- Final report on strategic opportunities and action plan for joint activities in eHealth (anticipated at month 27).

### **1.7 Objectives of this report**

As the final, public report of a Sixth Framework Programme project, the purposes of this report are fourfold. They are to outline the work intended to be undertaken in the project; list the project's objectives; describe the results of the project; and draw an appropriate set of conclusions<sup>28</sup>. In the case of a coordination action that aims at underpinning a crucial research policy, and policy development, area, the latter objective is considered to be of particular importance.

By adapting the objectives appropriate to technology-based projects to a coordination action, sufficient information is also provided on the project's developments to enable the Member States, but also other enquirers and interested parties, to request further information on the project from the project coordinator. The report should not only be, but is, considered to be suitable for publication.

### **1.8 Structure of this report**

This final report is structured in a manner that is geared to reflect the numerous outcomes of the coordination action that have taken place throughout its 27-month duration. This final report concentrates on the two core fields of interest, eHealth policy and eHealth RTD. The content-related work of the coordination was concentrated largely on two areas, with a focus respectively on eHealth policy (work package two) and on eHealth RTD (work package three). The second work package culminated in a strengths, weaknesses, opportunities, and threats (SWOT) analysis, which is planned for publication in Finland in a STAKES academic publication. Its immediate results are, however – as anticipated – brought together in a synthesis in this final report. The report also covers an overview of the dissemination activities of the coordination action. Finally, the report presents in an overview and outlook, a number of observations that could be used to develop further eHealth policy and/or eHealth RTD directions in the future.

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<sup>28</sup> Negotiation guidance notes for coordinators of collaborative research projects. Document available from europa website [<http://wc.europa.eu/>], downloaded 24 July, 2007.

## 2 Making known the eHealth framework

A key initial aim of the coordination action was to set up a consistent terminology to describe eHealth. The goal was to enable a clear and easily understandable description of

- the emerging role of eHealth in value systems that deliver healthcare, and
- the developing needs for RTD in eHealth.

Following a review of the available literature and an assessment of a small set of Member States and one international example, an overview of a consistent and coherent manner of portraying eHealth was outlined. It is referred to as the eHealth ERA framework.

While the framework was initially considered to provide only an incremental step towards defining a final outline, it inevitably formed the main axis of the framework definition. The diagram that was developed to illustrate the eHealth ERA framework has received much support, and relatively little criticism, over the project duration. It has over time emerged as a frame that is consistently supported by an increasing body of work in the field (e.g., European Commission policy developments on research policy and on innovation implementation).

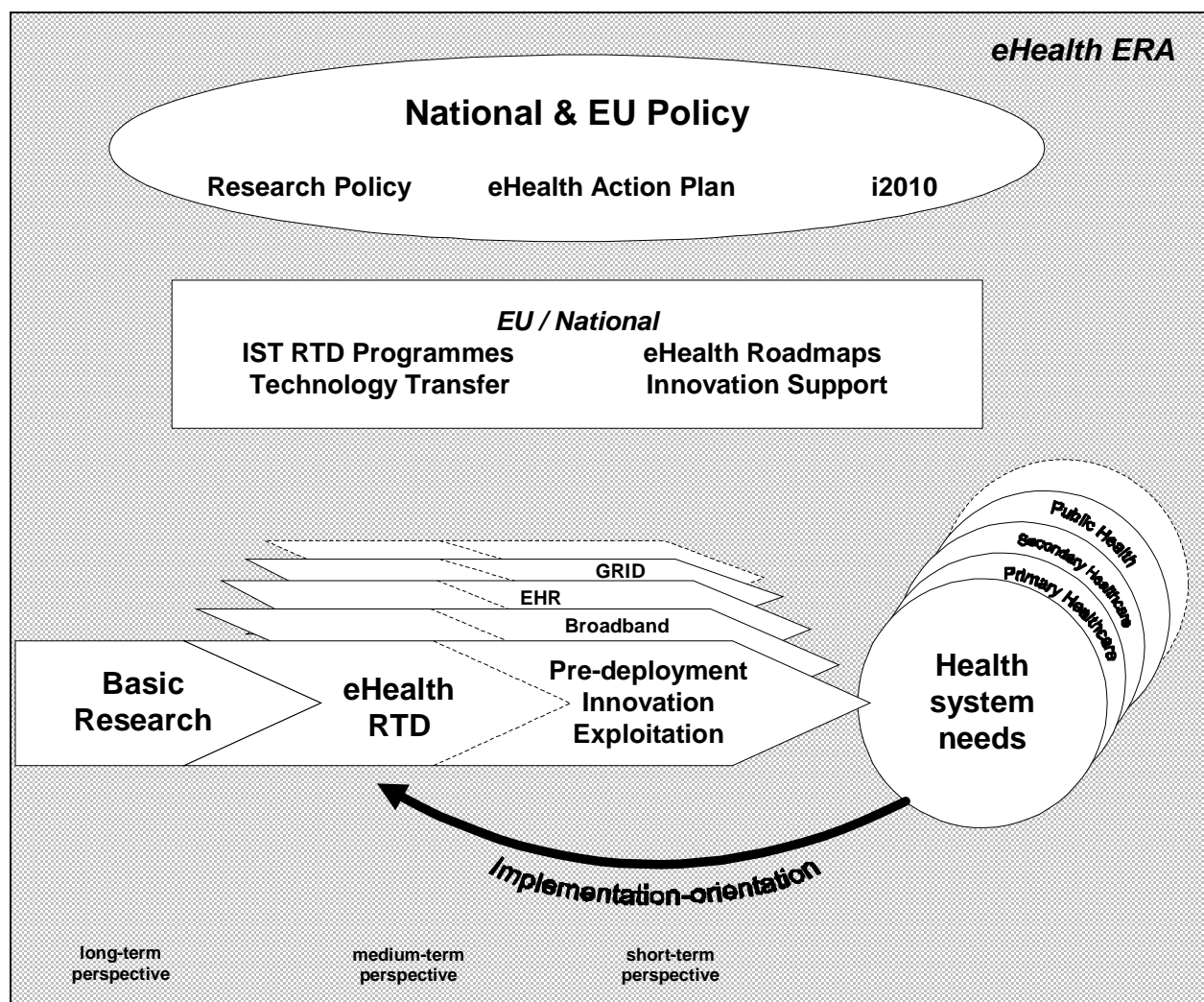
### ***2.1 Describing the eHealth ERA framework***

The framework identifies the policy instruments prominent during the time-period of the duration of eHealth ERA (principally, research policy, the eHealth action plan, and that part of the i2010 initiative related to eHealth) and places it within a context of technology transfer and support for innovation through both the IST RTD programme and the development of eHealth roadmap(s) at both European and national levels.

Crucially, the framework points to what has been termed an “implementation orientation” to the match between health systems needs and eHealth RTD. It shows that it is health system needs (at primary and secondary healthcare levels, and in the public health context) that influence eHealth RTD and surely clearly influence pre-deployment and deployment trends. Since these two domains tend to be of a shorter- and medium-term perspective, this relationship is not surprising. In this diagram, the relationship with basic research is not as clear, and is less easy to identify because of its longer-term horizons and higher-risk strategy.

The concepts underpinning the framework bear close resemblance to diagrams independently developed in the ICT for Health Unit to illustrate the synergistic relationship between RTD, implementation, and deployment.

**Figure 1: The eHealth ERA Framework**



### Explaining the eHealth RTD chain

Situated at the top of this eHealth ERA framework diagram are various EU policy initiatives, such as the eHealth action plan and the i2010 initiative with its particular orientation towards eHealth, as well as similar national policies. These initiatives point to the broad themes on which eHealth RTD is intended to focus. They include high-level strategies which, on their own, cannot lead to concrete results. Concrete programmes, initiatives, and support actions (the second level in the framework diagram) serve as tools to facilitate the implementation of the overall strategies. Together, these two levels guide and direct eHealth RTD in conjunction with other influences that include industry policy, independent sources of RTD funds, and legal and regulatory frameworks.

### The eHealth RTD chain

The actual research chain starts with basic research, which is not necessarily related to healthcare but can emerge from – or be shared with – other application domains such as

eBusiness, eGovernment or eLearning. Basic research has a long-term perspective, encompasses a fairly broad range of topics, and does not necessarily result directly in concrete applications. It can be seen as influenced both by general policies, as well as being independent of them, especially when – as in the case of the eHealth ERA framework – the policies are domain-specific. It was hypothesised that eHealth RTD, on the other hand, is driven more directly by eHealth roadmaps, programmes, and initiatives, and aims at very concrete applications for implementation in the health system.

eHealth RTD can be seen as a stage of application development in the short- to medium-term time horizon, with pre-deployment and innovation exploitation presented as the last two stages before an eHealth application becomes part of the actual country's or region's health system.

The eHealth RTD chain is located across a wide range of ICT. The varying focus of eHealth RTD activity is indicated by a set of RTD chains that each focus on a particular area of ICT which can contribute to supporting eHealth applications. Examples include broadband (applied, say, to health consultation), Grid technologies (when they handle specifically health application issues), electronic health records, or home-based platforms (for example, for advanced home-based health or care provision).

Any health system should not be regarded as a homogenous entity in terms of the supporting technology applications it requires. As examples, accident and emergency healthcare services may need applications that improve time management, whereas secondary healthcare services might be in need of applications that focus on treatment of patients. An electronic health record application – and its subset, the patient summary – could address both needs. Other eHealth solutions may have to be more specifically targeted.

In line with emerging eHealth policy, throughout the duration of the coordination action, it was vital to ensure that ICT was seen as a tool and not as an end in itself. At the same time, the slow uptake of eHealth applications suggests that RTD should be improved to remove or lower implementation hurdles. This crucial feature of the eHealth ERA framework is shown by the arrow connecting health system needs with the 'actual RTD' chain. It is the needs of the health system that have to feed the concrete content of research. Key components of understanding health system needs include prototyping and simulated or real implementation attempts, hence the use of the term "implementation orientation".

Finally, the eHealth ERA framework diagram focuses on public sector actors, especially with regard to the higher levels of planning. Non-government actors can also influence eHealth RTD through activities that include their own initiatives, lobbying, cross-sectoral synergies and spillovers. Examples of such actors particularly include industry organisations, but also involve charities or not-for-profit organisations, health professional groupings, patient representative groups, health insurance agencies and mechanisms, and other interest groups that are concerned by or focused on healthcare and/or RTD.

## **Outcome of the analytical framework**

This analytical framework – the eHealth framework – became a key element of all the work conducted throughout work package two of the coordination action, and supported all the interpretative analysis of the relevant materials collected through the duration of this work package. In designating generic topics and thematic clusters, accordance with the analytical framework was assured. Furthermore, the perspectives revealed by the analytical framework development were applied to the overall objectives of the eHealth ERA coordination action

as a whole. Thus, they contributed to the prioritisation of those eHealth implementation topics that were subsequently selected for joint activities (that is, patient summaries and patient empowerment). Equally, the framework influenced the thinking which lay behind the coverage of activities related to an overview of EU Member State eHealth RTD.

## 2.2 Other eHealth ERA methodological tools

Four core methodological tools were also drawn up as a result of the formulation of the eHealth framework. These were as follows:

- a review of definitions of eHealth and eHealth RTD
- the development of a core set of eHealth terms and concepts
- the development of a glossary of eHealth terms
- a list of possible eHealth benefits, outcomes, and potential indicators.

These four tools are reviewed briefly here. Two of them are supported by additional material provided in ANNEXES 2 and 3 (the glossary of eHealth terms and the list of eHealth benefits). Firstly, an outline is given of the various definitions of eHealth and eHealth RTD.

### eHealth definition

The coordination action drew on different bodies of work from a variety of researchers and policy-makers that aimed to clarify the definitions of eHealth. It thereby aimed to identify a brief, concise, and usable term for eHealth. On the research side, the work of Eng, Eysenbach, and later particularly of Pagliari and colleagues, which dates back to 2000-2005 were used as sources (Eng, 2001<sup>29</sup>; Eysenbach, 2001<sup>30</sup>; Pagliari et al, 2005<sup>31</sup>). On the policy side, the definitions used in policy documents such as the 2003 eHealth European Ministerial Declaration, the 2004 European eHealth action plan and, latterly, the 2007 Lead Markets Initiative<sup>32</sup> have also influenced the project's thinking. As noted in the eHealth ERA Draft Framework Report (August 2005), it was: 'appropriate to use the term *eHealth* in its broadest sense, accompanying any and all *ICT-based applications and services in the context of the health and care sector*' (Deliverable 2.1<sup>33</sup>, p13).

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<sup>29</sup> Eng T. *The e-Health Landscape – a terrain map of emerging information and communication technologies in health and health care*. Princeton NJ: The Robert Wood Johnson Foundation; 2001. URL: <http://www.rwjf.org>. Cited in Pagliari et al. 2005

<sup>30</sup> Eysenbach G. What is e-health? *J Med Internet Res* 2001 Jun 18;3(2):e20

<sup>31</sup> Pagliari C, Sloan D, Gregor P, Sullivan , Detmer D, Kahan JP, Oortwijn W, MacGillivrays S What Is eHealth (4): A Scoping Exercise to Map the Field. *J Med Internet Res* 2005;7(1):e9 <URL: <http://www.jmir.org/2005/1/e9/>>

<sup>32</sup> A document proposing a European-wide position on so-called lead markets, with a special reference to the role of eHealth in this is in preparation by the European Commission and is due for official publication in autumn 2007.

<sup>33</sup> eHealth ERA - Deliverable 2.1, Part 1, *Draft of analytical framework and information gathering instrument*, submitted 18 October, 2005.

Eventually, it was concluded that a broad definition of eHealth needed to be used, and one that could be considered pan-European. Among the most serviceable of these definitions the following notion was developed: 'eHealth encompasses applications of ICT that provide benefits to health' (eHealth ERA, Deliverable 2.1, p14). This definition became the coordination action's working definition of eHealth.

### eHealth RTD definition

As the coordination action succinctly identified:

'eHealth need not be defined as RTD, [and] with an appropriate definition we could talk of eHealth RTD and distinguish [those] from mature eHealth applications, which do not require RTD allowing them both to belong to eHealth' (eHealth ERA, Deliverable 2.1, p11).

The term 'eHealth RTD' was therefore selected to cover the various forms of RTD that can be undertaken in the eHealth field, and was distinguished from 'not-eHealth' or 'non-eHealth' issues. The initiatives incorporated in this field of RTD were seen to lie in the domain of health and other ministries. This finding is later supported by the project's investigations into the eHealth RTD environment (see Deliverable 3.1 'Report on national eHealth RTD programmes, approaches and institutions'). eHealth RTD was seen to incorporate firmly 'health system needs'. It was also defined as 'implementation-oriented RTD'.

### Collections of eHealth terms

Three collections of terms relating to eHealth were identified and analysed along the distinctions of the eHealth ERA Framework that emerged. These distinguished particularly between the domains of ICT and health system needs. The three collections of terms are:

- Types of information transmitted for telemedicine applications from the Space and Advanced Telecommunications (SATs) study
- The *medical informatics scientific content map* endorsed by the International Medical Informatics Association
- The collection of descriptors generated by Pagliari *et al*, 2005, at the outset of their search for a definition of eHealth.

The result provided confirmation that a small set of terms such as "ICT system" and "eHealth service" could be used to describe the eHealth domain. Two main ways of combining terms to create an eHealth system term are not included, but are included as component parts. These are:

- Constructing an eHealth term out of a general ICT term by adding a healthcare-specific term. Examples include placing terms such as people, organisation, activity or purpose ("health", "health professional", "hospital", "laboratory", "surgery" ) before the name of a general ICT system such as "hospital information system", "health professional workstation", "laboratory data", or adding a healthcare context after the ICT system term like "wireless networks in hospitals".
- Constructing an eHealth term out of a healthcare activity or purpose by adding "computer-supported", "computer-aided", "electronic", "digital", "web-based" "online", "e-", "tele-" or "distance" to a healthcare activity. The terms become, for example, "computer-supported surgery" , "computer aided instruction", "e-diagnosis", "online

health information". Also, by adding "aid" "support" or "tool" after the healthcare activity or purpose: "decision support", "diagnosis aid".

In addition to these, other constructions of terms were also decomposed, particularly "database", "information" and "message". A number of other terms were excluded for other reasons. Examples for exclusion include the following seven cases:

- Messages are described mainly by their use, i.e., "message for <activity, purpose>", e.g. "appointment booking message".
- A database or information collection is described by its coverage (e.g., "population database") or the group or clinical topic it addresses (e.g. "diabetes information").
- Terms for unique items rather than for generic concepts were also ignored, e.g., "NHS-Net".
- Specific fields of the activity/purpose "research" are not mapped as these are invariably composed as "<knowledge domain (discipline)> research" e.g., "pharmacology research".
- Ideas such as the "potential of <ICT item> for new applications" could not be mapped.
- Some examples of more recent ICT very are evidently missing, such as blogs, instant messaging, push to talk, and social networking.
- Analogues to eHealth, ICT and terms at a similarly high level of abstraction – such as telehealth, telematics, telemedicine, e-business – are also not included.

For an overview of these findings on the collections of eHealth terms, please see ANNEX 3.

## **eHealth benefits**

The coordination action identified a set of eight possible purposes, benefits and outcomes if and when appropriate eHealth applications were to be soundly integrated in the Member States: integration and coordination; quality; transparency; speed; efficiency; mobility; security and data protection; and safety and risk management. (For an in-depth overview of these findings on eHealth benefits, see ANNEX 3.)

The following are eight important types of benefit which it is considered that appropriate eHealth applications can bring to European health services. They are integration and coordination, quality, transparency, speed, efficiency, mobility, security and data protection, and safety and risk management. They provide criteria for evaluating health system outcomes, and can therefore be used as possible output metrics.

### Integration and coordination

Support for treatment processes by giving easy access to a wide range of medical data. Integrating and bringing together data from different sources such as laboratories and medical records, and data from external service providers. This integration implies the need to ensure the right information at the right time for the right people.

### Quality

Improve the quality of care and outcomes achieved. Important approaches such as disease management and case management should be supported.

### Transparency

Create transparency across the continuum of care for patients, professionals and payers. Without this, a patient-focused approach will not be possible.

### Speed

Assure efficiency by quick delivery of services as well as decrease the time to develop and release new drugs and medical devices.

### Efficiency

Apart from combining quality and speed, incorporate the economic view of healthcare services, which includes improving the efficiency of processes for coordinating and billing of care delivery.

### Mobility

Enable information recall and collection wherever it is needed. No matter whether this should be: at the bedside visit (chart information system), while travelling (smart phone, or personal digital assistant (PDA)) or in a computer centre (portals, hospital information systems).

### Security and data protection

Prevent loss of data or inaccurate storage, and maintain the personal and data protection rights of persons.

### Safety and risk management

Improve patient safety, and support proactive culture of risk and error management. Proactive analysis of healthcare processes and automated alert and reminder systems should prevent errors before they happen.

Chart adapted from eHealth ERA, Deliverable 2.1, p47

### 3 eHealth priorities and strategies in European countries

Never before has there been a concrete, comprehensive overview available of what the EU and its Member States are doing in relation to eHealth.

Today, as a result of the survey and review work undertaken by the eHealth ERA coordination action throughout 2006 a large-scale review of all the European eHealth priorities and strategies is available. This review was published at the end of March 2007 under the *aegis* of the European Commission<sup>34</sup>. The work undertaken to complete this publication was supported actively by various correspondents and actors in its network, a network of Member States' representatives, and the Coordination Committee. The overview was ready in time for release and announcement at the high-level eHealth conference 2007, held in Berlin, Germany, in April 2007. It was one of the items of most interest to visitors to the European Commission exhibition stand on which the document was on display.

This so-called fact sheet summary, which is entitled *eHealth priorities and strategies in European countries*<sup>35</sup>, provides a comprehensive overview that charts the developments in the 27 Member States and other European countries in terms of their individual eHealth roadmaps and action plans. It shows just how much the Member States are committing their energies to making progress on the European eHealth agenda. While eHealth is currently advancing in several individual countries, it is clear that the next stage could and should be large-scale connectivity and interoperability throughout Europe of the various eHealth systems. A more structured roadmap for interoperable eHealth solutions throughout Europe – that is currently underway in the context of the proposed draft Recommendation on eHealth interoperability – would support continuity of care, cross-border provision of health services, and a more sustainable and high-quality eHealth market in Europe. It would do this by

- Deploying high-quality eHealth solutions
- Responding to patients', citizens', and health professionals' needs, and placing even more importance on access, quality, cost, and safety of healthcare
- Reinforcing both innovation and industrial potential.

It would thereby create a win-win situation could be created for a wide range of European stakeholders.

The Member States have responded enthusiastically, and have given wide support to the explicit motivation provided in the 2004 eHealth action plan 'to develop a national or regional roadmap for eHealth' in their own nations. Depending on their starting-point in terms of these activities, the Member States have either initiated, strengthened, or fostered their plans for eHealth. They are now moving much more pragmatically towards the implementation of eHealth systems and services throughout Europe<sup>36</sup>. The degree to which there is consistency and coherence in these plans was explored by the eHealth ERA coordination

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<sup>34</sup> European Commission (2007) *eHealth priorities and strategies in European countries*. eHealth ERA report – March 2007. Brussels: Belgium

<sup>35</sup> European Commission (2007) *eHealth priorities and strategies in European countries*. eHealth ERA report – March 2007

<sup>36</sup> See eHealth Conference 2007 Declaration, the Draft Recommendation on eHealth interoperability, and the Member States' plan to cooperate in the context of a large-scale pilot on eHealth.

action in its overview of these initiatives in the factsheet summary report, specifically in the chapter entitled 'Towards a smart European health space'.

### **3.1 Towards a smart European health space**

The shared values and goals of European Member States operating in cooperation with each other are reflected in the motto of the 2007 German Presidency of the EU 'working together'. This concept of joint and common activity was also reflected in the eHealth Conference 2007 Declaration title and the declaration's content<sup>37</sup>. There, the vision of eHealth that reflects a consensual commitment to enable a more coherent and collaborative provision of healthcare throughout Europe is spelled out explicitly. The EU has shifted to a position in which eHealth is now recognised widely and publicly as a key enabler of good health, perhaps most dynamically by its health authorities. As the use of ICT in healthcare provision in Europe expands, so to there is a parallel orientation towards healthcare as health rather than care, and citizens as active consumers and transformers of health and its positive results rather than as passive or 'patient' recipients of care. eHealth is facilitating a solution to the European nations' pressing collective need to face their common European challenges. The 2007 fact sheet summary's overview explains concretely how this process is taking place, and what the trends and outcomes are in the various European Member States.

### **3.2 Addressing common European challenges with eHealth**

Twenty-two European governments have published a statement on their eHealth position since 2003. While many Member States started work only in this field over the past five years some, such as Denmark, Finland, and Norway, began already in the mid-1990s. Many countries link their endeavours to other electronically-related initiatives such as the eHealth action plan, the i2010 initiative (or, formerly, the eEurope initiative), and the concept of knowledge-driven societies or the Information Society. Over two-thirds of countries' health policies undoubtedly support directly by what they want to do with eHealth. For ten of these countries, eHealth forms part of their health services' strategy; for fourteen, they also focus on notions of cost containment, efficiency, and quality in healthcare. For thirteen countries, eHealth was one of the subjects in their eGovernment strategy. In particular, England, Ireland, and Portugal take a citizen-centred view of eHealth.

The responsible bodies are largely ministries of health, but some countries illustrate a more widespread range of responsibilities. Several ministries are involved in Belgium and Italy, for example. While Austria has a very federal system for handling eHealth, Finland and Spain both have more decentralised systems. More than a dozen countries have also set up various consulting bodies and/or competent authorities (under ministerial supervision) to handle the implementation of eHealth within their own borders.

Operationally, the factsheet summary overview concluded from the evidence collated that policy administration and monitoring structures are not sufficient to deploy and develop further eHealth structures. What is needed are more concrete plans for action which have very focused goals and objectives. A harmonisation with regard to these would facilitate the next steps into the actual introduction of eHealth in many of Europe's nations.

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<sup>37</sup> See eHealth Conference 2007 declaration: [http://ec.europa.eu/health-EU/news/ehealth/ehealth2007\\_en.html](http://ec.europa.eu/health-EU/news/ehealth/ehealth2007_en.html)

However, potential new risks appear to be on the horizon – particularly with regard to the lack of understanding or attention to the requisite regulatory or legislative frameworks needed to deal with eHealth in the different countries. It is possibly for this reason that the following countries acknowledged that they are developing legislation in a number of areas: patients' rights (Belgium), privacy (Belgium, Ireland), certification of patient records-related software (Belgium), public health information (Estonia), and digital signatures in six countries (the Czech Republic, England, Estonia, Latvia, Lithuania, and Poland).

Among the implementation activities current in the European Member States are the planning and deployment of comparable eHealth infrastructures that serve all health providers, electronic health records, patient summaries, interoperability, support for Europe's mobile citizens, legislative and regulatory frameworks, and impact and assessment of eHealth. For the latter case, while England and Ireland have impact assessment schemes operating, Bulgaria, France, Slovenia, and Slovakia all have initiatives planned.

Finally, overall, the degree of attention on the part of the countries involved to eHealth training and development was low.

### **3.3 Planned future eHealth activities**

European Member States are therefore showing a strong commitment to move forward on eHealth. In the domain of eHealth implementation, there is a wide range of anticipated or already planned activities. The most common two initiatives are the notion of the electronic health record and national health information infrastructure schemes. These two activities come top of the list in the information provided by fifteen and thirteen countries respectively. ePrescribing was nominated by twelve countries. Other core initiatives include eCards, interoperability and standards, and a legal mechanism that can support the appropriate eHealth mechanisms. This keenness mirrors what is known today about the enthusiasm of the Member States for the large-scale pilot schemes in eHealth proposed by the EC's Competitiveness and Innovation Programme Policy Support Programme<sup>38</sup>, with their focus on patient summaries, and especially emergency data sets, and ePrescribing. These are also areas of involvement that, not unsurprisingly, have a certain amount of synergy with the Member States' requests for the eHealth ERA coordination action to dedicate a core portion of its work to investigating patient summaries and patient empowerment through eHealth.

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<sup>38</sup> Competitiveness and Innovation Framework Programme (CIP) ICT Policy Support Programme. *ICT PSP Work Programme 2007*.

## 4 Defining a patient summary

An economically sustainable evolution of the healthcare sector – which would lead to more efficiency, effectiveness, and higher quality and safety – requires improved communication among healthcare professionals, the provision of timely data to healthcare managers, and an understanding of their health status by patient themselves. Patient summaries could be a key component of this context.

Today, suitable ICT infrastructures are being deployed, and several kinds of paper-based workflows are being transformed through a document-based approach to electronic clinical communication<sup>39</sup>. The clinical documents involved include: prescriptions (medications and procedures), diagnostic orders and reports (laboratory and images), hospital discharge summaries and patient summaries. Moreover, several comprehensive national and regional programmes are currently managing various kinds of clinical documents as "persistent objects". That is, they store the documents securely in repositories, index them in a common registry, and make them accessible to appropriately authorised persons.

### Recognising the importance of patient summaries

One of the activities in the second work package of the eHealth ERA coordination action was designed to assist the Member States, represented by the project's Coordination Committee (which was at that time known as the eHealth Working Group<sup>40</sup>), in the analysis of, and recommendations about, one of two relevant Topic Clusters for further research and action. This overview of the activities on patient summaries is drawn from this report (D2.3 'Patient Summaries'), hereafter referred to simply as the Patient Summaries Report.

The eHealth ERA Coordination Committee recognised that patient summaries are a key priority for Europe. It requested the eHealth stakeholders' group<sup>41</sup> to perform a short survey that would focus comprehensively on the issues related to patient summaries. The eHealth ERA coordination action therefore agreed at that stage to concentrate its work on patient summaries. As a consequence, a survey was organised by the eHealth stakeholders' group, with the assistance of the eHealth ERA coordination action, to collect preliminary evidence about the state of development of the initiatives on patient summaries in a number of selected countries.

### Findings on patient summaries

Half of the 17 answers received to the survey were from official bodies (Ministry of Health or National Competence Centre). The survey was designed as an exploratory activity which would give an overall sense of the various types of patient summaries, and of the potential topics for further discussions on summaries. It was not designed to uncover detailed

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<sup>39</sup> These are paper documents transformed into electronic documents, not alterable and electronically signed, stored – if needed – in a safe repository and made accessible through the network only to authorised persons.

<sup>40</sup> A Committee made up of representatives of the Ministries of EU Member States and the Commission Services, now renamed as i2010 subgroup on eHealth.

<sup>41</sup> A task force made up of representative of industries, municipalities, associations and coordination projects

information about each country that was surveyed. Such an aim should be tackled by other, further, specific research or survey activities.

The eHealth ERA coordination action used the survey as a starting point to inspire a systematic analysis of the patient summaries field. The findings are now presented as an output of the first Topic Cluster. The document provides the basis for further studies and policy recommendations; it provides a language and proposals for actions to make further progress on the topic; and it explores the opportunities for collaboration among the various Member States in Europe. The survey and its accompanying document conclude:

- Patient summaries are a key component of eHealth roadmaps in several European countries.
- The concept of a patient summary is not yet unique and stable. The features of the various patient summaries depend largely on the characteristics of the particular eHealth programme in which they are embedded. Overall scenarios for the deployment of patient summaries depend on strategic decisions that are made in each national and regional jurisdiction and which influence the specific format and use of clinical documents.
- Besides patient summaries, most European eHealth programmes also involve the development and use of various kinds of clinical documents in electronic formats, such as prescriptions and diagnostic reports.
- A precondition for patient summaries is the deployment of suitable infrastructures that identify suitably both citizens and healthcare professionals, the availability of repositories and registries for the management of clinical documents across healthcare facilities, and the application of appropriate security and confidentiality measures.

### **Potential for future work on patient summaries**

Further investigations (that were undertaken with the ongoing support of the eHealth ERA project on its first Topic Cluster) compare the contexts and scenarios in which patient summaries are deployed in each European jurisdiction with the functions and the internal structure for the summaries. A small task force was organised this activity. The progress and success of this patient summary initiative is mirrored by the parallel decision that ensures that the Competitiveness and Innovation Programme (CIP) Policy Support Programme (PSP) selected the emergency data record/patient summary as one of the fundamental eHealth applications to be explored in the context of a large-scale eHealth pilot initiative to take place throughout a three-year time-period (2008-2010) in the EU.

## 5 Defining patient empowerment through eHealth

The Report on Priority Cluster Topic 2 Analysis is the outcome of the fifth work task allotted to work package 2 (Deliverable 2.5). From here onwards, it is referred to simply as the 'Patient Empowerment Report'. This report provides materials and recommendations that were used as input for the third phase of the project. This third phase of the project was the creation of a strengths, weaknesses, opportunities, and threats (SWOT) Analysis.

The study undertaken covers eHealth-based systems and tools that can empower a range of health consumers including citizens, patients, their families and caregivers. The scope of the study incorporates any ICT-based system that enables citizens to have more choice and control over their own healthcare – a scope which is far wider than just use of the Internet. The report contains a review of a large collection of eHealth applications: they range from technologies like some quite simple web sites to complex collaborative ICT systems that can support the concept of 'ubiquitous personal care'<sup>42</sup>. The analysis in the Patient Empowerment report covers:

- Defining the scope and content of patient empowerment
- Mapping patient empowerment activities across the EU
- Identifying major activity lines, key issues and trends in patient empowerment
- Identifying the potential for areas of recommended action.

The Patient Empowerment Report offers a basis for the further analysis of patient empowerment. It opens up some real, new, opportunities for co-operation on eHealth in the EU.

The Report's four key successes are: its overview of the current state-of-play of patient empowerment in Europe; its unique 80-case study review of eHealth-facilitated patient empowerment; its development of a new process model of motivation that will facilitate new research directions in eHealth-facilitated patient empowerment – known as the access-competence-motivation model; and its uncovering of important new areas in eHealth that require further research and investigation.

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<sup>42</sup> 'Ubiquitous personal care', while it fundamentally implies personal care that is available anywhere, it could also mean anytime, and any place.

### **5.1 The eHealth ERA framework**

The project team analysed a representative sample of 80 eHealth patient empowerment applications that are taking place in a large number of the EU Member States. The team designed a practical classification scheme to analyse the complexities of the reality of patient empowerment. This taxonomy has a two-step approach. The first classification group includes five basic sets of technologies (voice, data, health, ICT, and personal care systems). The second classification group defines a classification for each of these sets.

### **5.2 ICT-supported patient empowerment and its roles**

Patient empowerment is a central element of the EU's health strategy. Europe's independent national health authorities, the European Council, and the World Health Organisation European office also all support the ideal of patient empowerment. Europe's experience of patient empowerment facilitated by eHealth::

- Provides access to trusted information and advice
- Supports patient education for health literacy
- Implements the process for patients to access and manage their own health data through an electronic Patient Health Record (ePHR)
- Increases patient security and convenience (through eAppointments and ePrescribing)
- Facilitates online health behavioral modification (known as 'self-care'), and
- Supports new electronically-based models of chronic care (known as eChronic Care).

Since the publication of the Communication on the quality of health-related information in 2000<sup>43</sup>, the EU has supported several initiatives that address the quality of health information provided by health-related websites. In parallel, it has launched the EU Health portal, and has co-funded projects under the 5FP and 6FP, the eTEN programme, and the Public Health Programme (this last is led by DG Health and Consumer Affairs).

Many of today's eHealth national and or regional health patient-related health systems strategies are based on patient empowerment as a guiding principle. However, not all eHealth applications – even many of those that claim to have patient empowerment features – actually do support patients.

### **5.3 The wider implications of ICT and patient empowerment**

European citizens' most relevant sources of health information are the official portal sites supported by governments or by healthcare agencies. These portals provide information and advice about health, illnesses, and health services. They enable patients to make sound decisions about their own healthcare and that of their families. These portals coordinate their own information with that provided by other information channels such as telephone call centres and channels on digital television.

In most European countries, electronic Patient (or Personal) Health Records implementation is still in its early stages. The electronic personal health record systems that are currently

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<sup>43</sup>COM(2002)667 final. *eEurope 2002: Quality Criteria for Health related Web Sites*

available are provided by a number of providers: they range from public healthcare services to private health insurance groups, and include commercial companies.

Health authorities across Europe are very interested in how to implement new models of chronic care models – how to support people who may have long-term diabetes or heart conditions – and how to use ICT tools to do this. Most of the experiences implemented are based on a notion of disease management that is handled by patients themselves together with their clinic or hospital.

Europe's increasingly wide diffusion of eHealth-facilitated patient empowerment tools is favored by general trends in technology push, and the promotion of both eHealth and the Information Society across the Union. The take-up also reflects the market pull of consumer demand, combined with that of medical doctors, healthcare organisations, and governments. Yet, there is also resistance to this trend. It originates with certain healthcare organisations, professionals, and also consumers. These stakeholders show concern about the gap between high-level political declarations and the relatively slow pace of adoption and day-to-day use of eHealth tools.

Europe is facing many common challenges, and themes and opportunities for cooperation. Of course, different European countries have different views of how to encourage patient empowerment. But, current trends indicate tremendous opportunities for RTD and innovation in eHealth-facilitated patient empowerment. While patients will benefit, such an approach can also reinforce the strength of Europe's eHealth markets because it will create new products and solutions that are addressed more effectively to the demands of European society.

#### **5.4 Development of an access-competence-motivation model of patient empowerment**

The eHealth ERA coordination action also made great strides in developing a model for analysing patient empowerment. This original analysis can facilitate further, new research directions. The team formulated a model that it calls the access-competence-motivation model. It is often referred to simply as the ACM model. The model represents the tendency of European patients to adopt electronic services ('eServices') as a function of the three factors: access, competence, and motivation.

To improve *accessibility*, the model proposes an emphasis on the use of mobile technologies and services. Future research developments would add value to the notion of ambient intelligence that would be very much aligned to the RTD priorities of the 7FP. A focus on accessibility would also be very much in line with the EU's eInclusion policy and its commitment to ICT use by elderly and disabled persons. Patient education can promote patients' *competence*. Research efforts in the eHealth field on 'personalised patient education', with the use of electronic personal health records at its base could offer considerable benefits to European patients and their ability to help themselves. In terms of *motivation*, people are more motivated to use eHealth systems that have visible benefits and solve actual health needs. Hence, it would seem appropriate to concentrate research on eHealth that supports both chronic disease-related and elderly care.

Table 2 (below) shows how different strategic actions and mechanisms for encouraging patient empowerment can be classified to different types of ICT, and how all of these are in turn related to the access-competence-motivation model. Different ICT provide a better fit of responses to the eight targeted populations which are derived from the model. These eight populations of patients/citizens each have a different profile or degree of access, or

competence, or motivation. See the Roman numerals I-VIII in the most left-hand side column of the table.

<b>Table 2 Strategic actions, patient empowering mechanisms, and type of eHealth application</b>			
<b>Targeted population</b>	<b>Strategic action: the aim is to undertake the following</b>	<b>Patient Empowering mechanism</b>	<b>eHealth Application</b>
I: ACM	Increase offer of services	Communication Personalised information Patient education. Health literacy Chronic care	mHealth ePHR Educational tools eChronic care
II: AcM	Increase motivation	Patient Education. Health literacy Chronic care	Educational tools eChronic care
III: AcM	Increase competence	Design for all Accessibility Patient education. e- literacy	Educational tools Inclusive eHealth
IV: aCM	Increase access	Applications using Mobile terminals Accessibility	mHealth Inclusive eHealth
V: AcM	Increase eSkills + motivation	Patient Education. e-literacy Chronic care	Educational tools eChronic care
VI: aCm	Increase accessibility + motivation	Mobility Accessibility Patient Education. Health literacy Chronic care	mHealth eChronic care Educational tools Inclusive eHealth
VII: acM	Increase accessibility + eSkills	Mobility Accessibility Patient Education. e-literacy	mHealth Inclusive eHealth Educational tools
VIII:acm	Increase access + eSkills + motivation	Mobility Accessibility Patient education. Health & e-literacy Chronic care	mHealth Inclusive eHealth Educational tools eChronic care

Table adapted from Deliverable 2.5 ‘Patient Empowerment’.

ICT provide many of the technical applications that can facilitate the implementation of patient empowerment applications. However, there are a number of aspects to patient empowerment that lie beyond technology, and which form part of the new social and relational context of the emerging Information Society. A major challenge is to integrate eHealth patient empowering tools and systems into standard healthcare processes, organisational structures, and technological infrastructures, and to ensure that they are interoperable with other health information systems. In this context, the acceptance and active involvement of the wide range of all health professionals' into the philosophy and the process of patient empowerment must also be carefully considered.

Analyses performed using the access-competence-motivation reference model would enable a focus on future actions in the patient empowerment arena that would match the specific needs of different population groups. Conversely, proposed patient empowerment action lines would take into consideration the different profiles of targeted consumers, thus articulating efforts for maximising efficiency. The proposed patient empowerment lines of action are intended to improve the three axes of access, competence, and motivation. Such a strategy is aligned clearly with current EC policy, i.e. on mobile technologies; ambient intelligence; chronic care and eInclusion.

This second Priority Topic Cluster covers eHealth-based systems and tools that can enable the empowerment of health consumers, i.e., citizens, patients, their families and caregivers. The Patient Empowerment report provides the opportunity for greater awareness about the actual situation around Europe in concrete terms with regard to the current status of patient empowerment, and has uncovered the main trends in practical patient empowerment implementation in EU countries. The eighty cases collected offer references to good practices that aim to improve access to and quality of care by supporting a variety of patient-empowering eHealth implementation approaches.

### ***5.5 Conclusions on patient empowerment***

While there is diversity in patient empowerment approaches across Europe, there are nevertheless certain common themes and common challenges as they relate to eHealth. One of these commonalities is the gap between high-level declarations and the delay in practical adoption of eHealth tools. A decade ago, many people had optimistic expectations about the development of Internet-based applications in medicine and health (let us call this eHealth). Over the last few years, however, these hopes have been transformed into more realistic scenarios in which the various Member States' national/regional plans for eHealth in Europe often act as the principal drivers. Over the same timeframe, eHealth applications to enable patient empowerment have extended their capacities from a first wave of quite simple Internet-based tools into a range of complex collaborative systems to support chronic care. Current trends indicate opportunities for RTD and innovation that could reinforce the creation of a European eHealth market with new products and solutions that address the demands of European society.

Across Europe, a growing interest in personal health records has led to developments and initiatives at both the national level and at a smaller scale. The two main purposes of introducing personal health records have been to empower patients with a sense of ownership of their own healthcare, and to improve communication between patients and clinicians, and between the different clinicians involved in particular patients' care. Introduction of web-based personal health records is considered by some authors to have revolutionised communication between patients and healthcare professionals. However,

sharing sensitive electronic health information must be based on a new level of trust between patients and the health professionals and organisations that serve them, as well as among the various health occupations themselves.

The implementation of eHealth applications that serve a patient empowerment philosophy highlights certain needs that extend further than traditional eHealth preoccupations. Currently, understanding of these kinds of requirements, design principles, and implementation issues is quite limited. Progress in this combined research and application field could benefit from further studies which would help to develop theoretical models of patient empowerment, articulate the conditions under which patient empowerment occurs, and clarify the role that eHealth tools can play in this process. Examples of issues that merit further study include: how patients can view and control their own electronic personal health records, and what exactly they may mean for patient empowerment. In particular, interdisciplinary study is needed to explore not only the technological requirements of patient empowerment, but also to address the formal analysis and modelling of care processes, interoperability of different health information systems, organisational barriers, deployment strategies, and the consequences of creating collaborative healthcare information systems.

## 6 Analysing eHealth strengths, weaknesses, opportunities, and threats

The eHealth ERA coordination action work plan defined the work to be done on the two Priority Topic Clusters as a basis for a SWOT analysis. It offers a good option for grounding the analysis on two concrete themes within eHealth. These two themes, of patient summary and patient empowerment, have received widespread support from the general European constituency as important stepping-stones to developing further pan-European thinking and acting on eHealth, particularly in terms of implementation and deployment. Particularly, the patient empowerment theme, however, also offers further research opportunities in the field of organisational behaviour and change management.

### 6.1 Aims of the SWOT analysis

A principal aim of the eHealth ERA project was defined as coordinating the planning of national innovation-oriented eHealth RTD as the basis for a common European roadmap and joint RTD activities. It is towards this goal that the analysis of Strengths, Weaknesses, Opportunities, and Threats (SWOT) is also targeted. SWOT is a subjective assessment of data organised in a SWOT format that helps decision-makers to understand, present, discuss, and make decisions in this case about an organisational proposition or idea, i.e., about what areas to concentrate on in terms of future eHealth. A SWOT analysis can be used as 'a strategic planning tool used to evaluate the Strengths, Weaknesses, Opportunities, and Threats in any situation requiring a decision.'<sup>44</sup> The objective of the SWOT in eHealth ERA was defined as "[c]reating a joint view of the European eHealth "priorities" and 'targets for joint activities', which was further focused on an 'analysis of conditions for joint eHealth implementation in Europe'. In the eHealth ERA project, the SWOT is thus applied to a coordination action rather than a company.

### 6.2 SWOT analysis methodology

The SWOT analysis was performed by using a content analysis of the two Priority Topic Cluster reports. Methodologically, three coding rounds were performed: open coding to create preliminary content codes grounded in the text; axial coding arranging the content codes under relevant business categories; and the assignment of each content code with the property of a strength, weakness, opportunity or threat. After the coding, commonalities were searched for across the data. The table that follows (Table 3) shows the completed, *a posteriori* definitions used for the different areas of the eHealth community.

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<sup>44</sup> This quotation, as the others in relation to SWOT analyses, are taken from the SWOT analysis report.

**Table 3. The *a posteriori* definitions of the SWOT elements**

Element	Definition in the literature	eHealth ERA definition
Community	Company (department or organisation)	The European eHealth Research, implementation and policy makers community
Objective	reviewing a strategy, position or direction of a company or business proposition, or any other idea.	Analysis of conditions for joint eHealth implementation in Europe
Purpose of SWOT	To get the management team to agree on and commit to a comprehensive set of action for change/development	to identify what the Member States could do together to facilitate integrated and interoperable European health information space
Methodology	group session.	Two-phase approach 1) desk-top analysis of selected reports focussing on two eHealth application areas 2) group session on validating - further developing the desk-top analysis results
SWOT	<p>1. Strength = internal activity performed well, advantage, asset, identified strength of the community</p> <p>2. Weakness = internal activity performed poorly, identified critique, complaint, vulnerability</p> <p>3. Opportunity = External change in environment (organisation, technology, policies, socioeconomics and demographics) which we know of, which can be exploited, emerging trends to be exploited</p>	<p>1. Strength = current attribute or phenomenon within PE or PS activity that paves way and supports development of joint activities (known advantages of production, customers, distribution, finance and administration of PE or PS)</p> <p>2. Weakness = current attribute or phenomenon within the PE or PS activity, identified need or requirement that impedes joint PE or PS-activities (known disadvantages within the business categories)</p> <p>3. Opportunity = suggestion, proposal, possibility, future phenomenon, activity that is likely to support development of joint PE/ PS activities (anticipated advantages of production, customers, distribution, finance and administration of joint PE and PS)</p> <p>4. Threat = challenge, condition phenomenon or activity visible in the</p>

	4. Threat = External factor that blocks our progress, competitor's advantages, change anticipated in the markets, weaknesses that make us vulnerable	future that is likely to hamper development of joint PE or PS activities (anticipated disadvantages within the business categories)
Business categories	<ol style="list-style-type: none"> <li>1. Product (what are we producing and "selling")</li> <li>2. Process (How are we producing and selling it?)</li> <li>3. Customers (to whom are we selling?)</li> <li>4. Distribution (how does the product reach the customers?)</li> <li>5. Finance (at what price do we produce?)</li> <li>6. Administration (how do we manage and develop all this?)</li> </ol>	<ol style="list-style-type: none"> <li>1. Product = concept or idea of PE, PS. The expert group suggested that it is through these and other eHealth activities that Member States are in fact trying to promote "mobile Health"</li> <li>2. Process and distribution = Deployment: application fields, application tools and their diffusion</li> <li>3. Customers: Users (citizens, professionals, organisations, national healthcare systems), needs, contextual features</li> <li>4. Research and management of (joint) PE and PS activities. The expert working group discussion emphasised that the question of financing should also be included in this category.</li> </ol>
Competitors		eHealth communities in other continents (Asian, north and Latin American, African, Australian) to the extent that they can be identified, focussing on implementation.

Legend: PE = patient empowerment; PS: patient summary or summaries.

The ensuing conclusions are based on these commonalities: they refer to strategic actions to use strengths, reduce weaknesses, exploit opportunities and protect against threats in the eHealth area. The initial analysis was first complemented by commentaries made by the eHealth project team and later by an expert group session that was specially organised in order to comment on and elaborate the results of the SWOT analysis.

### **6.3 eHealth strategies – the Ten Commandments**

The SWOT analysis produced ten conclusions that are referred to as "the ten commandments". They are intended to outline the proposal of strategic actions, for consideration by the Member States, that can be undertaken jointly by them in two domains of eHealth activity – that is, patient summaries and patient empowerment. They are outlined in Table 4 (which is to be found immediately below).

**Table 4 - eHealth strategies: The Ten Commandments****Joint view of European eHealth concepts**

1) Joint minimum definitions of the thematic areas and related concepts (e.g. patient empowerment and patient summaries should be created.

**Joint view of European eHealth deployment**

2) Jointly defined target activities for cross-country deployment should be generated for different sectors using existing experiences and use cases, national objectives and studies on stakeholder needs and requirements. Challenges regarding cross-border care quality and cost should also be resolved. Challenges regarding cross-border care quality and cost should also be resolved.

3) In deploying the jointly defined target areas, a shift in emphasis from techno-centric development to co-construction of work, client and information processes and organisation of services, entailing stakeholder participation, should be encouraged. Due to differences in the health service delivery systems and their regulation in different Member States, special attention should be paid to searching for commonalities in the work, information and client processes as well as the organisation of services.

4) Common technological issues that have already been identified, including security, management of registries and repositories, mechanisms for feeding and accessing data and certification, should be worked on further.

**Joint view of European eHealth users and contexts of use**

5) Attention should be paid to equal access, inclusion, stakeholder involvement and participation issues in order to enhance the value of solutions for key stakeholders and thereby facilitate wider adoption and acceptance of eHealth solutions.

6) Users' competence and motivation to deploy eSolutions (for patient empowerment or patient summaries) as well as producers' competence to develop acceptable solutions should be increased through education and training.

**Joint view of European eHealth management and research**

7) National eHealth strategies and roadmaps should be further developed to operationalise the objectives and activities, milestones and timelines to enhance the collaboration of countries that have similar targets and timelines.

8) The Member State objectives, evidence on the use cases, cross-border activities and users' needs and requirements should be collected and analysed to inform decision-making about and management of joint eHealth activities.

9) Management of information on current situations, trends, objectives and progress should be made more public and transparent. It could be used as the basis for benchmarking and of planning of collaboration.

10) Apart from the issues mentioned above, research should also be conducted on evidence of costs-benefits and impacts of eHealth for different stakeholders, policies and legislation.

Both patient empowerment and patient summaries have been influenced by many current eHealth development trends. The orientation towards the use of patient summaries and encouragement of patient empowerment is becoming more realistic through the growing diffusion of ICT.

The results of this SWOT analysis indicate that a first step in elaborating the results could be to identify and analyse the experience of concrete, ongoing joint activities ("joint" is understood here to mean collaboration among countries), use cases, and potential, future, joint activities within different eHealth topics, where there are shared objectives possible among Member States. These data could steer the eventual selection of concrete targets for joint activities as well as the conditions for their development between the different countries.

As complementary background material, the two Priority Topic Cluster reports, on which these ideas are based, present concrete suggestions on the future activities needed in the two areas of patient summaries and patient empowerment. They too describe a basis for the further analysis of opportunities for cooperation on eHealth in the European Union.

Methodologically, there were, nevertheless, some limitations to the SWOT analysis that impact the reliability of the results. Instead of generating the analysis in a working group session, the preliminary conclusions were drawn on an analysis of the two Priority Topic Cluster reports. These two reports were quite different in content and character. The definition of the "organisation" involved i.e., eHealth decision-makers was somewhat elusive, and consisted of a loose community of policy makers, implementers and researchers of eHealth issues in Europe. To reduce the impact of these limitations, the SWOT analysis was subject to comments and feedback on several occasions. These included discussions of the *a priori* definitions in a Madrid project group meeting in December 2006; an email round of comments that took place in February-March 2007; discussions in a Krakow project meeting in April 2007 and, finally, a three-hour expert meeting organised by the eHealth ERA project and held in Brussels in June 2007.

While the present activities of the eHealth community (whether in RTD or in deployment terms) remain quite dispersed, they pose a challenge for the definition of the possibilities for joint activities. Slowly, the eHealth community is, however, consolidating, although more in the deployment field than in the RTD field. In this sense, therefore, the observations that result from the analysis of eHealth RTD (see chapter 7) provide a number of complementary guidelines to the SWOT analysis.

#### **6.4 Summary of the key outcomes of the SWOT study**

Equally important to agreeing on the joint Strengths, Weaknesses, Opportunities and Threats of eHealth is the need to propose actions that should be taken jointly on the basis of these results. The preliminary list of the suggested joint actions, and its condensing into a preliminary list of "Ten Commandments", was updated with the feedback from a final expert group meeting. This meeting indicated much potential for a willingness to act in a joint approach, both among the Member State representatives and stakeholder representatives present. Overall, the expert group meeting did not contradict any of the "ten commandments". As one of the experts put it succinctly: *"I could agree on most that has been said."*

Placing an emphasis on careful analysis and implementation of solutions based on the analysis, one Member State representative stated: *"We have identified two opposed approaches in our development: Some stakeholders prefer to implement fast and see what*

*happens, others to define use cases, the needs, and then to implement solutions to the needs. The ten commandments and the expert working group discussion clearly speak for the second alternative, and offer a guideline for gaining user acceptance."*

The way towards the proposed developments has been paved by many current development trends. Demographic trends as well as rising healthcare expenses act as strong drivers for these developments. Patient empowerment and patient summary scenarios are becoming more realistic with the development and diffusion of contemporary ICT like the internet and mobile telephony. Both concepts are complex and pose a challenge for interdisciplinary research and development as well as some of the technical issues to be solved. The Priority Topic Cluster reports present a number of concrete tools (like the ACM model) that focus on the future activities needed, and present a basis for further analysis on opportunities for cooperation of eHealth within the EU.

The task of defining, let alone acting on, the agreed action points is demanding enough in a corporate world where the business, actors and activities are well defined. The difficulties are magnified in the EU eHealth context, where none of these elements are as well delineated. To facilitate as much as possible a path towards decision followed by action, a decision was made to concentrate on a SWOT analysis that was based on two in-depth studies. The first study was on patient empowerment, and the second on patient summaries. A preliminary proposal for the SWOT analysis, translated into proposed actions, was also performed. This too was further elaborated in the final expert working group session. These proposed actions merely still represent a preliminary view of the suggested actions across so-called business categories (referred to as "the ten commandments" of actions for joint eHealth); areas where the Member States could work together and facilitate cooperation. This view needs to be further elaborated; verified; and the suggested actions prioritised with Member States in order to develop adequately a roadmap for further joint eHealth activities. The eHealth policy makers' community is now responsible for how the results are further elaborated and used to support their decision-making. It is sincerely hoped that a positive and pro-active approach can be taken to this opportunity, especially considering the other, multiple health and eHealth responsibilities and challenges to which the Member States are currently subject.

The ultimate question that remains to be answered after agreeing on the results is who and how to *act* on the actions agreed - in corporate terms 'what shall the team do' about the issues in each of these categories. This approach captures the collective agreement and commitment (*motivation*) of those who will ultimately have to do the work of meeting or exceeding the objectives set. It permits the eventual, agreed team leader (whoever or whatever he, she, or it may be) to define and develop coordinated, goal-directed actions, which underpin the overall agreed objectives among levels of the organisational hierarchy. Gaining wide acceptance and translating the SWOT issues into actions in each of the categories that result from the analysis makes them more quantifiable and measurable, the responsible teams more accountable, and therefore the activities more manageable.

The results indicate that the first steps in prioritising the results and elaborating them further could be in three areas. These are as follows: first, to identify and analyse the experience on concrete, ongoing joint activities ("joint" is understood here to mean collaboration among countries); second, to develop use cases; and, third, to create potential joint activities on different eHealth topics where there are shared objectives among Member States. Concrete targets for joint activities as well as conditions for their development could then be jointly defined between the appropriate number(s) of Member States.

## 7 Outlining what is happening with eHealth RTD

This chapter describes, first, the perceived status of eHealth RTD at the beginning of the eHealth ERA project; second, the initiatives undertaken to analyse further eHealth RTD in Europe; and, third, conclusions drawn with regard to actions to be undertaken that could strengthen and enhance the field of eHealth RTD in Europe.

### 7.1 Absence of European-wide eHealth RTD coordination

At the start of the eHealth ERA coordination action, it was determined that, at the policy level, little or no RTD and implementation coordination was to be observed across the Union other than individual Framework Programme co-financed projects. As was detailed elsewhere<sup>45</sup>, various RTD and infrastructure activities were in existence in individual Member States. Some cross-border health service delivery schemes had also been piloted (although, they had limited eHealth support). In a few cases, these had even been routinely implemented<sup>46</sup>. However, at the RTD level – to the project team's knowledge – no informal or structured information exchange was taking place apart from the occasional EC-organised so-called 'concertation'<sup>47</sup> meeting. Only exceptions to this observation have been uncovered by the project's own research over the last twenty-four months.

### 7.2 Lack of national level RTD activities

At the beginning of the eHealth ERA coordination action, it was suggested that no comprehensive overview existed of national-level eHealth RTD and innovation activities. Some Member States had introduced national strategies for ICT applications in healthcare in the mid-1990s and had revised them in more recent years<sup>48</sup>. Stimulated by both the need to make healthcare delivery more efficient and to meet Union-level initiatives and European-wide or external competition, some countries had developed more comprehensive RTD initiatives, including roadmaps for eHealth and eHealth deployment plans. Among the key priorities of these strategies are: eHealth research and deployment with respect to Electronic Health Records (EHR), communication infrastructures and/or networks, standardisation, security and privacy, and improved national and international collaboration.

This chapter outlines those aspects of this eHealth RTD study that are of crucial importance for European-level and for national-level eHealth RTD policy-makers. It reviews briefly the important methodological aspects of this inductive content-based analysis study. It outlines the salient findings of this eHealth RTD overview at both European and national levels that

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<sup>45</sup> See, e.g., Karl A. Stroetmann, Veli N. Stroetmann (2004): Electronic business in the health and social services sector - Key issues, case studies, conclusions. *Sector Impact Study No. 10-II*. The European e-Business Market W@tch, Brussels/Bonn, August 2004; available at <http://www.ebusiness-watch.org>. or: MEDITRAV Project (2002) (IST 1999-11490), Deliverable 1: The State of eHealth in Europe.

<sup>46</sup> For further information, cf. Karl A. Stroetmann, Veli N. Stroetmann (2004): *Sector Impact Study No. 10-II*, Case study on "Cross-border patient mobility and interoperability issues", pp. 34 ff.

<sup>47</sup> In this sense, 'concertation' implies a 'get-together' or an information-sharing exercise.

<sup>48</sup> Doupi, P. (2003): eHealth in Europe: Where do we stand? Tromso Telemedicine Conference, September 15-17, 2003, Tromso, Norway, [www2.telemet.no/ttc2003/pp\\_presentations/Doupi\\_Persephone.ppt](http://www2.telemet.no/ttc2003/pp_presentations/Doupi_Persephone.ppt)

have emerged from the data analysis and from the qualitative literature review. The chapter highlights a range of policy options for consideration.

### **7.3 Purpose of the eHealth ERA RTD review**

The eHealth RTD review undertaken as part of the eHealth ERA Work Package Three illustrates an advance on the two previous pan-European studies that undertook overviews of European-wide eHealth RTD. It provides a first, systematic scoping of the eHealth RTD field. As a result, it provides a possible structure and content for high-level, strategic future discussions on European-wide eHealth RTD. It covers three areas of concern: the opportunity to move ahead strategically on further European eHealth RTD; the need to assess and evaluate regularly progress in eHealth RTD; and the need for further studies on eHealth RTD.

The eHealth RTD review is a strategy-level insight into the European eHealth RTD landscape. It is a complementary document to various others. These include, firstly, the eHealth strengths, weaknesses, opportunities, and threats analysis of patient summaries and patient empowerment and, secondly, a number of the road mapping exercises that are outcomes of European Commission co-financed eHealth support actions in such fields as bio-informatics, eHealth semantics and ontologies, and eHealthgrid initiatives.

As an outcome of this eHealth RTD review, it is suggested that the European Commission might wish to hold an eHealth RTD-related symposium (for example, within the context of a major eHealth event) that enables brainstorming at the most strategic level with regard to future possible scenarios for European-wide eHealth RTD, including the launch of a European eHealth RTD Area. Such a foresight and brainstorming exercise could test out the proposals and suggestions put forward in this chapter.

### **7.4 eHealth ERA RTD review methodology**

Several core definitions of work underpinning the field of eHealth RTD were developed. In terms of topics, RTD fell into clear categories of 'eHealth' and 'non-eHealth'; the category of what constitutes 'eHealth' RTD is broad, and comprises such fields as health information, health information systems, bio-informatics, health and medical sciences, and other eHealth. The principal two sources of funding mechanism at the national level were defined as 'programmes' and 'other than programmes'. Information gathering was undertaken on both primary and secondary sources of data. The eHealth RTD situation in twenty-eight countries was investigated and assessed, and the data analysed using inductive content analysis. As a result, findings were made possible in relation to three specific areas in relation to eHealth RTD in relation to a wide range of European Member States. A fourth area – national eHealth RTD activities – did not provide sufficient materials to assess its findings here. The three areas of attention were:

- descriptions of national eHealth RTD
- stakeholder involvement in eHealth RTD
- funding mechanisms for eHealth RTD

A number of observations can be made with regard to information available on three other topics. These are: international collaboration, a lack of common terminology for describing eHealth RTD, and methods for identifying eHealth RTD activities.

## **7.5 Descriptions of key findings at national and international levels of eHealth RTD**

The following descriptions outline the core findings in the three areas identified in the description of the study methodology.

### **Descriptions of national eHealth RTD, and which countries are leaders**

As illustrated by the INNOCULT study, eHealth RTD appears to be one of the key eleven priority areas of research in Europe. Finland, France, Germany and the UK seem to be Europe's leaders in terms of the breadth of the research topics that are being pursued in these countries that are potentially relevant to eHealth. Generally, however, this study shows that a wider spread of countries is involved in eHealth RTD than was first identified by either the INNOCULT or the CISTRANA study.

This study identifies that there were no national-level programmes that focused solely on eHealth. In all the descriptions of national eHealth RTD research programmes reviewed, eHealth is only one of many research areas covered. In many cases, there is no explicit mention of eHealth among programmes' goals. Instead, there is a considerable variety of levels of description available from country-to-country. A number of countries previously unidentified by past studies as having an importance in the eHealth RTD area are shown to do so; examples include Belgium, Denmark, Estonia, and Latvia. Use of standardised research classifications, in this case the IPPA, helps to ground the analysis of the topics of eHealth-related RTD, but does not go far enough in this support.

The extent to which country-specific information can be extended or extrapolated to European levels of observation is questionable. Nevertheless, it is important to consider that any approach to a pan-European eHealth RTD area needs to bear in mind an approach which could provisionally cover all the European Member States.

### **Stakeholder involvement in national eHealth RTD**

More than four hundred stakeholder entities are involved in support of national eHealth RTD. This constitutes an average of over fifteen eHealth RTD stakeholders in each country in Europe (sometimes many more; frequently less).

A review of stakeholder relationships in this study suggests that at the country level the relevant ministries and departments are the most important stakeholder group in creating any shift in RTD focus towards a European eHealth RTD area. This stakeholder group plays various key roles in the formulation of countries' general policy and strategy, and the determination of the level of funding allocated to eHealth RTD. Implementation agencies, such as programme implementation bodies and research councils, are the most active stakeholder group in terms of the number of relationships with other stakeholders. In addition to their general functions related to financing and implementation of RTD activities, implementation agencies act as key networking and information hubs between all the key stakeholder groups. The coordination of eHealth RTD activities is the activity most frequently performed at the level of the organisations conducting the relevant RTD, i.e., in universities and other research organisations.

In terms of relevance to eHealth, it is relatively easy to classify stakeholders involved in the technology transfer and implementation of eHealth applications. However, the higher the level of relevance to RTD, the more difficult it is to classify stakeholders in terms of their relevance to eHealth.

This part of the study was aimed at identifying stakeholders which would have the largest potential impact in achieving a step change in the area of eHealth RTD at a country level. The analysis permits consideration in countries with an as yet not well developed field of eHealth RTD research to consider the importance of certain stakeholders. Identification of stakeholder involvement could be extremely important in any future shift in the RTD activity of those countries towards the eHealth domain that are relatively undeveloped at present.

### **Stakeholder involvement in strategy or policy process**

The information sources available contained a significant amount of information about stakeholder interactions at the policy and strategy levels. Mostly, these activities were described in relation to general RTD policy, and referred less frequently or directly to eHealth. The policy formulation process is based on the monitoring and evaluation of current RTD activities, and the monitoring and assessment of opportunities for further development of strategically important areas of research. Policy formulation also involves continuous consultation processes carried out through various advisory bodies with the representation of stakeholders which act at all four levels of strategy formulation (policy, strategy, management and implementation).

Of prime importance in terms of stakeholder interaction are the eight categories of role which the various stakeholders perform. These roles are principally funding but also policy making, implementing, managing, coordinating, advice giving, monitoring, and collaborating internationally. Funding appears to be among the most important of these roles.

### **Eight national stakeholder groups**

Here a list is provided of the eight distinct stakeholder groups that were identified at a national level in eHealth RTD:

1. National ministries and departments responsible for research
2. Implementation bodies, Research councils and Funds
3. Universities and research organisations
4. Advisory bodies
5. National government
6. Academies
7. Health authorities
8. Regional and local authorities.

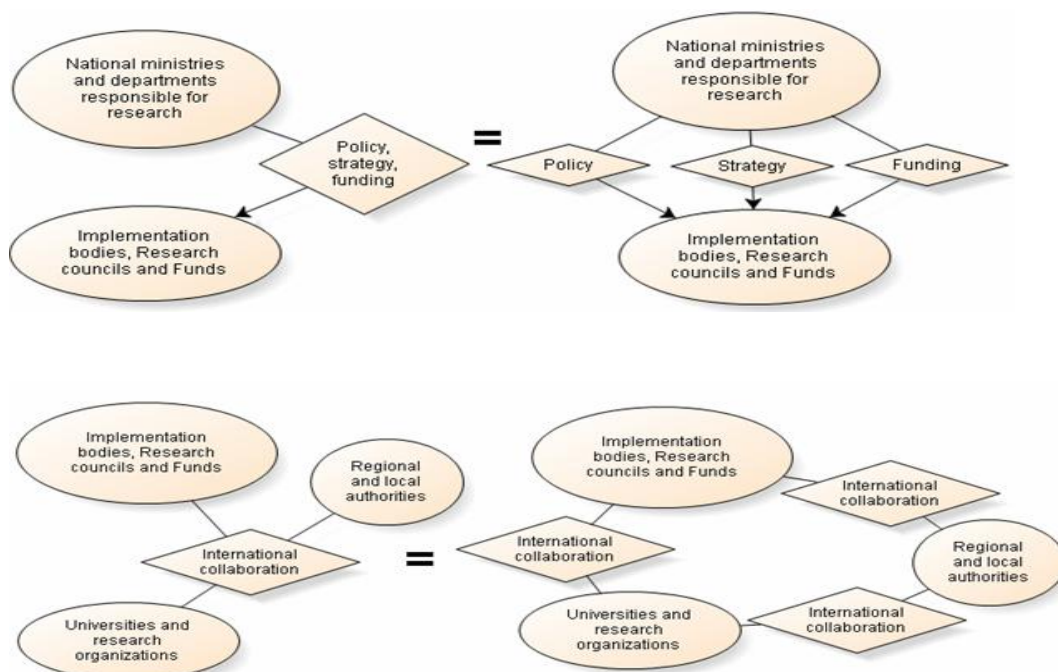
The primarily important stakeholder roles appear to be between the national ministries, implementation bodies, and the universities. It is feasible that all these stakeholders may be able to play an important role in expanding the eHealth research in these countries.

However, the following observations can be made about the remaining five stakeholder groups.

Advisory councils appear to have considerable influence particularly in two of the smaller European Union countries (Ireland and Malta); the extent to which this finding is applicable to a wider range of European Member States would need to be further verified. The stakeholder group of national government is most frequently mentioned in relation to general funding policy and implementation strategy for countries' RTD systems, again very often – with the exception of Germany and Poland – in relation to some of the smaller European countries by size of population. Academies have a major influence in the eHealth RTD field in only one Member State, Finland. Health authorities are only rarely mentioned in the terms of eHealth RTD.

Evidence shows that health authorities in some European countries are consistently mentioned in the context of the financing of RTD activities (for example, in Bulgaria, Finland, Germany, Ireland, Italy, and the UK). Qualitative information, on the other hand, indicates that health authorities are more concretely involved in eHealth deployment and implementation. Despite the fact that regional and local health authorities are not frequently mentioned in the RTD descriptions for the majority of countries studied, the role of regional health authorities is presented as being very important in the information sources in two particular countries: Belgium and Spain. This could suggest that there is a room for increasing the role of regions in eHealth RTD in at least these two countries, and perhaps others besides.

Summaries of the various stakeholder groups and relationships are outlined in the two diagrams below:

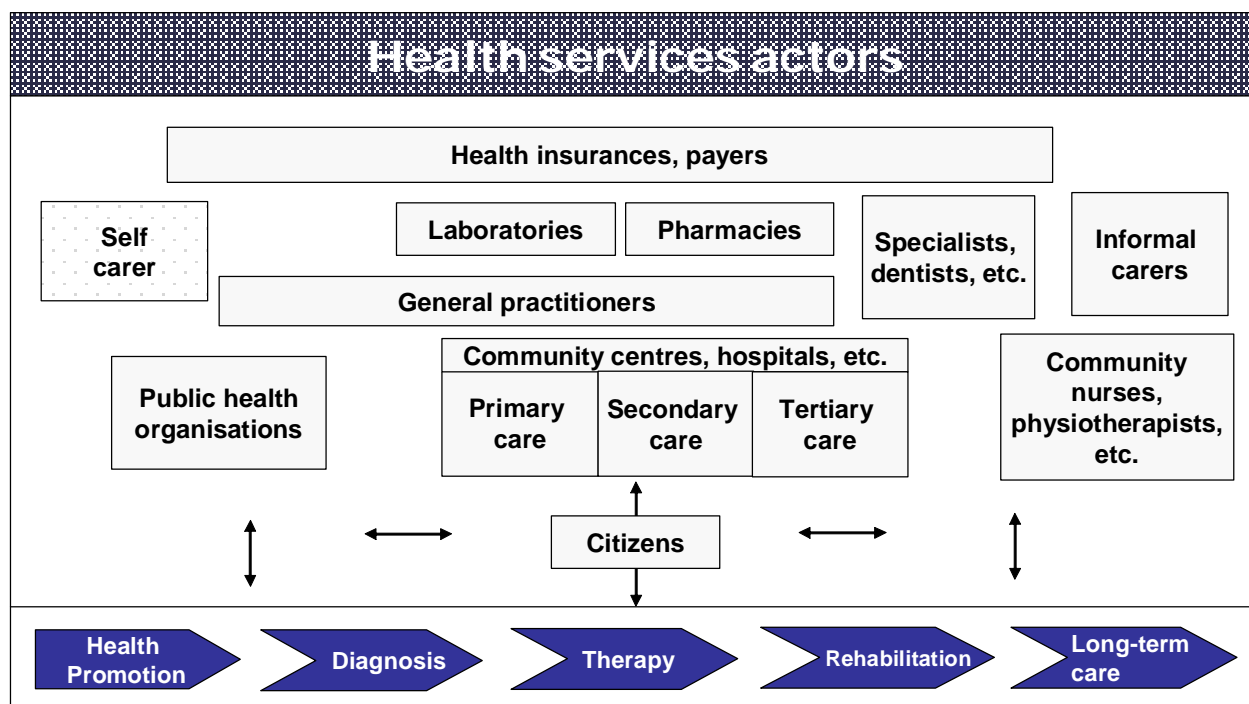


These observations with regard to eHealth RTD stakeholders mirror the identification undertaken of stakeholders in the eHealth deployment and implement field in the Semantic Health support action. There it has been identified that 'mapping the relationships between stakeholders is a challenge' and that '[t]he system is complex and differs from country to

country'. (SemanticHealth Deliverable, 1.1, p22). Clearly, use of ICT in healthcare is intended to facilitate communication between the various actors involved in the system. Two examples of data transfer using eHealth are described here: ePrescribing and public health records. Firstly, in the case of ePrescribing, all five stakeholders (general practitioners, nurses, pharmacists, informal carers and patients) need to communicate effectively. Data must be transmitted for the purposes of prescribing, appropriate reimbursement of any pricing mechanism, and other administrative purposes. Secondly, while health data are collected in the daily clinical environment: some of these are important for clinicians responsible for their own management or healthcare managers (for such purposes as planning, organisation, control), while yet other information could be used for personnel requiring to know about clinical outcome measurements, by public health statisticians, or researchers.

Figure 2 (below) portrays the various actors (stakeholders) involved in the health value system and its processes. These include general practitioners, personnel involved in general practices or hospitals in primary secondary and tertiary healthcare, laboratories, pharmacies/chemists, and other specialist healthcare practitioners such as dentists; health insurance schemes or agencies; public health organisations; nurses, informal carers; and the citizens/patients themselves.

**Figure 2: Illustrative map of actors and processes in the health value system**



Source: © empirica, 2006

### Funding mechanisms for eHealth RTD

Currently, national funding for eHealth RTD takes place rarely at the levels of programme-based funding. It is more likely to exist on a project or an institutional basis. In addition, at these lower levels of funding mechanism, there are some indications that European countries underutilise such mechanisms as project-based and institution-based funding.

The most important forms of funding mechanism are: programmes, a mix of programmes and non-programmes, and non-programmes. In detail, an analysis of the information reviewed suggests that six countries with the largest numbers of activities, Austria, Finland, France, Iceland, Sweden and UK, have a mix of programme- and non-programme funding types of activities. Programme-funded RTD activities only has a greater level of importance overall, since it is identified as relevant to eHealth RTD in more than half (15) of the 27 countries: Bulgaria, Estonia, Germany, Greece, Hungary, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Spain, the Czech Republic and Turkey. Non-programme types of funding mechanisms are known to exist in many of these countries in other RTD areas. However, the information sources reviewed did not contain any references to these mechanisms in the eHealth RTD context. Only non-programme-type funding was identified for eHealth RTD in these four countries: Ireland, Italy, Slovenia and Switzerland. Logic suggests that the larger the number of eHealth RTD activities in a particular country, the more diverse could be the range of organisational and financial arrangements.

Stakeholder analysis identified five groups of stakeholders that were most frequently referenced in relation to the financing of eHealth RTD activities: national ministries and departments responsible for research; various implementation bodies/research councils; universities and research organisations; advisory bodies; and academies. By far the two most important of these are the national ministries or departments and the implementation bodies/research councils.

The second most frequently mentioned stream of funds comes through the project-based mechanism administered by research councils and research funds.

In applying for project funding research organisations participate in defining the set of research topics which is finalised during the process of evaluation of research proposals. This process allows research organisations to be successful in gaining funding for curiosity-driven research. Analysis of information sources suggests that the potential exists for countries, and certainly for international collaboration on research, to coordinate or centralise much more strategically the selection of eHealth RTD topics to be supported financially.

Institution-based funding is most frequently mentioned as a mechanism for the financing of research institutions that undertake problem-driven research in specific areas of responsibility of particular national ministries and departments responsible for research. The range of funded research topics is determined by research institutions in consultation with funding organisations. Research institutions that receive institution-based funding from the ministries are often related to those ministries administratively.

### **Additional observations**

A number of observations can be made with regard to information available on international collaboration, a lack of common terminology for describing eHealth RTD, and methods for identifying eHealth RTD activities.

The relatively low amount of information on international collaboration in the reviewed information sources suggests the need for EC's attention in this area. This study has identified good practices existing in this area in several countries. Experience of these countries could be useful for enhancing the Europe-wide cooperation in the eHealth RTD area.

Another gap in the organisation of eHealth RTD is the lack of common terminology for describing eHealth RTD activities. As it was frequently mentioned in this report, the relevance to eHealth depends on the context rather than the content of RTD in such areas related to ICT and information systems. Some degree of standardisation of eHealth terminology could facilitate both exchange of information among stakeholders as well as monitoring developments in this area, which would in turn support further expansion and extension of eHealth RTD activities.

The methodological challenges related to definitions of RTD activities and attribution of these activities to eHealth faced by this study allowed only qualitative conclusions to be drawn. Quantitative conclusions could be drawn only on the basis of a review of eHealth RTD activities at a project level, where the attribution problem can be resolved more easily. The results of this study could be used as a basis for designing such a survey in the future. Annexes to this report provide lists of organisations and institutions which could be used in the formulation of sampling strategy and methodological notes can provide insights in the approach to address the attribution problem.

Several possibilities for the identification of potential eHealth RTD activities exist. They involve the geographic and regional character of strategy development, and the levels of funding; the nature of international challenges; and the kinds of supporting decision-making and funding mechanisms required. It is perhaps too early to gain a full picture of their main process-related advantages in building good practice in research promotion in terms of Member State involvement. Nevertheless, this should be considered as an important potential activity on the part of Member States. Research consortia themselves, in finalising their projects, could be asked to reflect on how greater or more effective Member State involvement could take place; what worked well from this perspective; and what did not work well, in order to provide more effective information for *post hoc* programme analysis and evaluation. The focus on larger-scale and well-funded coordinated activities northern Europe is of some concern, and it would be important to assess the potential for growing strengths on the part of southern and eastern European geographic areas. The question is also moot whether it is possible not only to sustain, but also to increase, European funding in RTD especially in the face of international challenges. (At a national level, in 2007 China, for example, is about to hit the European average for commitment to RTD funding: see the *Financial Times*, June 12, 2007.)

## **7.6 Findings from qualitative analysis of good eHealth RTD practice**

Two main sets of findings result from the brief, qualitative assessment of good eHealth RTD practices. They refer to how to undertake good eHealth projects, and how to organise strategic-level initiatives to undertake high-level eHealth RTD.

Long past are the days when only two or three institutions from a similar number of European Member States could be involved in an RTD project. In terms of pan-European eHealth RTD, the specific projects examined (which were MyHeart, PIPS, and Netc@rds) illustrate the benefits of a) having created a research instrument such as the very large Integrated Projects, b) committing substantial amount of resources both financial and human to a particular scientific endeavour, and c) the importance of lengthy time-periods to secure concrete scientific, technical and organisational developments. Overall, the focus should be less on the particular range of Member States involved (although a representation of countries north, south, east, and west may always be advantageous) than an appropriate choice of high-level industrial and research players.

In addition to the well-established 20-year development of EC-sponsored and co-financed eHealth RTD (for example, Iakovidis, Dour, and Karp, 2007), in terms of international eHealth collaboration, there is a growing body of cooperation on eHealth RTD in Europe. These new eHealth RTD activities appear to be undertaken in two ways. Like activities promoted by the Nordic Council, they may be fostered by groups of European Member States and countries which decide to collaborate among themselves. Or, like activities now being supported by the Article 169 mechanism, they are instigated by initiatives taken by the EC in order to open up certain opportunities to interested Member States.

Clearly, collaboration in large-scale projects a) takes place either in a given geographic area or in a grouping of countries; b) involves key research and industrial players, with c) adequate research funding; and d) an intention to gain strategic importance in the field.

With regard to the article 169 mechanism, crucial criteria involve the size and dimension of the programme, its substantial funding over a five-year period of activity, its support from the EC, European Council and European Parliament, its focus on strategic intentions, and its involvement of key industrial players. Of considerable interest is the wide range of different Member States involved.

In terms of eHealth and/or specific domains of eHealth RTD (such as bio-informatics), it could be appropriate, for example, to:

- Foster the emergence of innovative ICT-based products, services and systems
- Create a critical mass of research, development and innovation at the EU level in technologies and services
- Improve conditions for industrial exploitation.

Finally, in terms of stakeholder involvement, these initiatives have involved multiple Member States (with an emphasis on more than two countries being partners in each project), and a variety of types of partner, institution, or organisation. In eHealth RTD, these partners have comprised technical, industrial, health authorities, and users (including hospitals, clinics, representative organisations from different disease groupings, and clinicians and patients). With a more deployment-related orientation, efforts have also been made over the past two-year period since 2005 to relaunch a dedicated input to the eHealth area on the part of users. On the one hand, an industry user stakeholder group has been launched; and, on the other hand, a user group has been initiated.

### ***7.7 Possible orientations to enhance European-wide eHealth RTD***

The virtuous circle of involvement and influence between basic research and innovation- and market-oriented research may be of crucial importance in sustaining and enlarging eHealth RTD in Europe over the next decade, and longer. While researchers need to be aware of market opportunities, policy makers must also be conscious of the more futuristic research possibilities that may affect actual healthcare provision some ten, fifteen, or twenty years down the line.

The following set of observations identifies, on the one hand, that there may be a number of concrete policy mechanisms that could already be put into place to initiate a European eHealth RTD area. On the other hand, there may be a range of further possible studies that could be undertaken to supplement the policy-makers' understanding of the field. Another option would be to ensure that, at the same time, as policy decisions begin to be made, further investigatory studies continue to be undertaken.

While resources should ideally still be found to encourage independent and anonymous research of a curiosity-based character, these could be provided at the national/regional levels in individual countries. It is evident that the overwhelming importance of eHealth RTD at a European level should have as its core intention to focus on research with certain key attributes for Europe as a whole.

### **Political commitment to findings of initiatives already undertaken**

Further actions at the EC level on organising dedicated eHealth RTD programmes would be beneficial for further progress in this area. It is proposed that greater political commitment could be made to initiatives and studies already undertaken. Initiatives could be undertaken either uniquely within the sphere of the Information Society and Media Directorate-General, or could be more likely undertaken in the context of appropriate liaison with the Directorate-Generals on Research; Health and Consumer Affairs; Enterprise; Employment, Social Affairs and Equal Opportunities; Market, and so on. These include:

- Undertaking initiatives related to chronic diseases, personalised health systems, and homecare, such as the Lead Market Initiative on eHealth.
- Adapting mechanisms such as the article 169 concept and the <intelligent pharmaceuticals> industrial mechanism to other appropriate areas of potential eHealth RTD.
- Building on the work already undertaken by such studies and support actions as RIDE, SHARE, SYMBIOmatics.

The study suggests that a keen awareness of process is needed whenever a decision with regard to organising a dedicated eHealth RTD initiative for the whole of Europe. Most mechanisms need long and incremental periods of development in order to ensure their solid foundation and eventual success. This timespan could be up to the period of 15 years (which was certainly the case of the launch of eHealth as a research topic in Europe in 1988, and the beginning of eventual large-scale of deployment investment, implementation, and appropriate organisation at the European and various national levels in 2004). At the same time, a feedback mechanism would be required throughout the installation and functioning of the mechanism, since organisational changes need to be made over such a lengthy time-period in order to respond to altering external conditions. A staged set of incremental, individual research initiatives ('joint RTD research') could also be advocated, since most successful, individual research projects appear to need a lengthy period of research commitment (e.g., 48 months), and are possibly also only successful as a result of a dedicated series of successive time commitments:

A possible mechanism for the development of a pan-European view of eHealth RTD (a European eHealth RTD area) is outlined below:

### ***Developing a strategic European view of a European eHealth RTD area***

Further eHealth RTD should ideally be undertaken at a European level and have a Community perspective, and be supported by European-level funding matched by equivalent country-level funding from Member States. Whatever the eventual content, the domains of eHealth RTD to be undertaken should be:

- of strategic importance

- driven by appropriate areas of importance from the perspectives of health policy (Information Society Policy Link Initiative, 2006), ICT policy, and research policy
- large-scale
- high-risk
- highly innovative
- with high impact
- and could also support implicitly Europe's advanced manufacturing and service industries, and/or knowledge management within the health service sectors.

### ***Undertaking a roadmapping exercise for a European eHealth RTD Area***

The relevant Member State and stakeholder partners could together develop ideas for:

- A common roadmap or roadmaps for a European eHealth RTD area that would cover both research content and the appropriate processes involved.
- Additional joint eHealth RTD activities.

The research topics for consideration could involve personalised health systems, telemedicine, bio-sensors, gene-related research supported by ICT, photonics, and other domains of research that are currently being identified (see e.g., the potential results of the ongoing IPTS-sponsored Scenarios4Health study, <http://www.scenarios4health.eu>).

### ***Joining forces among Member States across Europe, and internationally***

eHealth RTD should involve a range of stakeholder partnerships that support the policy commitments cited above. There is a probable need to build synergistic relationships among relevant research-oriented committees e.g., the Information Society Technologies Committee, and others.

The range of forces joined together could include the following:

- All Member States (subject to their own choice and availability) should be involved in the various domains of the research lifecycle (policy, funding, decision-making, validation, testing, implementation). A critical mass of countries and high-level research institutions needs to be developed.
- ∅ Initial core groupings of Member States (e.g., 8-15), could involve incremental enlargement of the numbers of Member States involved. Small sub-groupings of Member States (from 2-6 in size) could research specialist sub-domains in which they have specific expertise). Validation exercises should certainly be considered to be cross-European throughout the Union's entirety. If and when appropriate, they could/should focus on high-level European and international level events for testing and validation e.g., the World Cup (International Federation of Association Football – FIFA, World Cup), Olympic Games.
- ∅ Further pan-European support for such an initiative could occur through a) a pan-European RTD advisory group mechanism, and b) a not-for-profit eHealth RTD researchers' representative network or association.

- International collaborating partners outside Europe (e.g., from Australia, Canada, Japan, China, India, Latin or South America), and the US). policy commitments cited above. The range of forces joined together could include the following:

### ***A clustering approach among Member States***

Not every eHealth RTD domain chosen for high priority exploration would need to include all the Member States of the Union in its development and application. However, as initially indicated in the European partnering approach outlined above, an incremental approach to cross-European eHealth RTD development could be based on a clustering approach which could have either a multi-lateral or a bi-lateral dimension. Equally, such an approach could be based on a notion of partnering countries that share a critical research mass in association with ‘observer’ or ‘accompanying’ nations. That is, other member States could or should be included in an advisory or observatory capacity, so as to be able to take optimum advantage of the policy directions being taken and the research outcomes resulting.

Policy development in the European eHealth RTD area would nevertheless require feedback and input from all the Member States. All potential initiatives could involve a form of steering committee/advisory group that involves representation from the appropriate research arms of all Member States. Hence, the benefit to any country for which a particular eHealth RTD field is not yet considered important or well-developed is that they would nevertheless be party to obtaining key information on any results or findings that form part of the eHealth RTD research. Generalisable topics as well as the specificities of particular Member States could be explored, and – presumably – adaptation to the research requirements and orientations of both the larger and smaller countries, and those which are more nationally-organised and those which are more regionally-organised.

Large countries (examples could include France, Germany, and the UK), with important and considerable numbers of research institutions and researchers, may be able to build on their well-organised and internal, domestic eHealth RTD domains.

Countries with geographic, historical, and cultural links (examples could include the Nordic countries and the Baltic countries) could develop logical and coherent areas of eHealth RTD with synergy and importance for the several countries involved.

### ***Partnering at the national level(s)***

At the European level, there needs to be the involvement of:

- Leading research institutions.
- Core industry sectors and associations that represent the role of Europe’s key industries, support its key policy domains, and that also ensure ongoing commitment to its economically-important supporting small- and medium-sized enterprises. The exemplars uncovered by this study relate to homecare, medical imaging, and several other sectors. That is: 1. Homecare: electronics, infrastructure, middleware, healthcare, insurers, and sensors), 2. Medical imaging: radiology, cardiology, and health information systems, 3. Miscellaneous: Pathology, ophthalmology, pharmacology, and patient care devices.
- Associations of pure and basic research bodies with deployment and implementation-oriented bodies.

- Core user-related stakeholder groupings that represent e.g., a range of health professions and occupations.

The overall aim should be to ensure a degree of coherence and consistency among pan-European, national, regional, and institutional levels of eHealth RTD.

### ***Core stakeholders at the national level***

At the national level, organisations included in the national ministries group should be the first point of reference in introducing changes into RTD policies and organisational structures that support eHealth RTD. A careful assessment may have to be made about the appropriate ministries that are involved in eHealth RTD. These may range across health ministries, research ministries, innovation or industry-related ministries, core public sector services' ministries, and/or education ministries (see proposals for studies, below).

Implementation agencies (such as programme implementation bodies and research councils) could be the most effective point of engagement in increasing the level of eHealth RTD activities and developing research infrastructure within European countries. There is therefore a potential for improvement of coordination at the national levels through the involvement of stakeholders that act at the higher levels of stakeholder hierarchy, particularly at the programme and strategy levels.

### ***Ensuring appropriate funding***

Clearly, great benefit can be drawn from careful, instrumental use of the 7FP funding mechanisms in terms of ensuring substantial amounts of funding to key strategic eHealth RTD domains. These could/should involve:

- Continuing dedication of EC funding initiated in the 7FP (i.e, around 200 million euros per two-year period per strategic topic).
- At the national level, an aggregation and focusing of programme-based funding<sup>49</sup> streams allocated to eHealth RTD activities could be beneficial in the further development of research infrastructure and expansion of research in this area.
- At the national levels of funding, project- and institution-based funding could also provide additional tools for both stimulation of the curiosity-driven research and to focus eHealth RTD activities in new strategically important areas.

### ***Continuing evaluation and assessment of progress***

Further development of good practice concepts in eHealth RTD need to be developed especially in terms of:

- enhancing and enlarging community (stakeholder) development, i.e., developing communities of practice
- creating effectiveness and efficiency of resulting benchmarking and indicators

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<sup>49</sup> The definitions of funding mechanisms identified within this study are described in section 7.5.

- creating more 'learning points' and outcomes that are transferable, e.g., asking partners in successful consortia to make observations on good resulting content, mechanisms, and process.

### **Further studies**

Further studies may be required in a number of areas that involve a more detailed overall assessment field; the types of ministries involved in eHealth RTD, comparisons with European-wide research undertaken on eHealth in the 4FP, 5FP, and 6FP; the ranges of stakeholder involvement; various geographic and regional models of eHealth RTD support, and eHealth RTD classificatory systems or schemes. These six concepts are described briefly in further detail below.

- a study to determine those areas which require further study and analysis (coordination actions, support actions, studies through both the EC and its associate research bodies e.g., IPTS).
- a study or survey of the numbers and types of ministries involved in each Member State in the different aspects of eHealth principally including research. Other domains covered by eHealth, apart from research, that might be considered for survey coverage would include: public and private sector partnerships; legal and regulatory mechanisms; data privacy and security; implementation and deployment; education; the social service sector,
- a study to compare the findings of this study with materials (including statistical) available from the EC on the eHealth components of former Framework Programmes (particularly 4FP, 6FP, and 6FP).
- a study to assess appropriate stakeholder representation at European level; appropriate mechanisms of liaison between the European level and the country-specific level; and consideration at country-specific levels of appropriate coordination mechanisms. Consideration could be given to the various models available for eHealth RTD stakeholder involvement including e.g., France, Finland, Germany, and the UK.
- a study of countries with a regional model of eHealth RTD support. Such an assessment could examine the research support mechanisms appropriate in different national and institutional settings, particularly in relation to Member States with important regional orientations. Such an undertaking could be undertaken in relation with either the Committee of Regions or with other important regional-based or city-based organisations, such as the European Regional Information Society Association (ERISA) at <http://www.erisa.be/> or the WHO Healthy Cities network at [http://www.euro.who.int/healthy-cities/natl/20040714\\_1](http://www.euro.who.int/healthy-cities/natl/20040714_1)). Consideration could be given to the various models available in such countries as Belgium, Finland; France, Ireland; Malta, Spain.
- a study to assess the need for the development of a registry of systematic and standardised classification and recording scheme for eHealth RTD domains and/or further development of the IPPA classification scheme with respect to the relevant eHealth RTD domains.

## 8 Making eHealth ERA's results known to the public

The eHealth ERA coordination action has two main areas of commitment. It has made a considerable investment to ensuring that as many of its findings as possible are available to the eHealth community of decision-makers and, more widely, to the general public. The project team has attended a large number of high-level events and strategic meetings, organised many meetings of its own, and ensured coverage of its findings on its own website, and on the EC website and also, where possible, in well-advertised publications.

Making a project's results known to the public is known in European terms as 'dissemination'. The project team has concentrated its dissemination focus on making the coordination action's results and insights available to the wider European stakeholder communities, but particularly those in the six countries involved in the initiative. The project's web presence has thus been – and continues to be – its cornerstone. Getting information to the public has involved putting information and results on the project website; publishing articles and in-depth reports in the general press, and in the journals, magazines, and newsletters of the participating partners and health ministries. A project information flyer was printed and widely distributed.

Many public presentations at conferences, meetings and workshops formed part of this wider dissemination initiative. Key among these were five major events. A specific initial focus was on the organisation of an intensive one-day Forum session and workshop at the European Health Forum Gastein, in October 2005. Later, the project team concentrated on presentations and workshops at prominent events such as the High-Level eHealth Conferences in Malaga in May 2006 and in Berlin in April 2007; at the World of Health IT conference in Geneva in October 2006; and a networking session and workshop at the annual EU ICT Conference in Helsinki in November 2006. Project team members attended other major, international events in Australia, Canada, and the US as strategic opportunities arose, and often at the direct request of the European Commission. All the project partners, but especially the project coordinator, were actively involved in this process. They were ambassadors for the project's message about Europeans working together for eHealth in Europe.

A major success is in some ways the culmination of the project's activities: its handbook that outlines all the European countries' current priorities, strategies, and roadmaps for eHealth, published just in time to be launched at the eHealth Conference 2007 attended by 1,000+ people. This 'hot-off-the-press' publication flew off the conference exhibition stands that were hosting it.

A review of the eHealth ERA coordination action's dissemination activities shows how the project team has worked to assess the appropriateness of different dissemination tools for the different target audiences selected. The project team assumes that the media used in each specific case have particular strengths for attracting the attention of certain target groups. Figure 3 (below) illustrates the assessment.

**Figure 1: The appropriateness of eHealth ERA dissemination tools for seven key target groups**

		Electronic		Paper-based			Oral		
		www	News-letters	Project flyer	Scientific articles	Public journals	Brochure	Workshops	Confer-ence presen-tations
<b>Target groups</b>	<b>Member State Governments</b>	+	++	++	++	-	++	++	++
	<b>European organisations</b>	+	++	++	++	-	++	++	++
	<b>Research community</b>	++	++	++	++	-	+	++	++
	<b>Healthcare professionals</b>	+	++	++	++	+	++	+	++
	<b>Hospitals</b>	+	+	+	+	-	++	+	+
	<b>Health insurers</b>	+	+	+	+	-	+	+	+
	<b>General public</b>	++	+	+	-	++	-	-	-

Legend:                    ++ = Very suitable    + = Suitable    - = not suitable

Source: eHealth ERA D4.3 ‘Dissemination Report’

eHealth ERA’s website presentation particularly suits the general public and the eHealth research community. The project newsletters are well suited to a range of readers that includes four target groups: the Member State governments’ representatives, European organisations, the research community, and healthcare professionals. eHealth ERA’s flyer, its scientific articles, and its conference presentations are attractive mostly to these four target groups. Public magazines are optimal for members of the public. eHealth ERA’s brochure is a very good medium for all the target groups with the exception of the general public and, to some extent, health insurers. A high-quality publication, well-written and well-targeted publication with good content and excellent opportunities for advertising support on the part of industry, health authorities, and insurers could be of considerable future interest. Finally, project workshops have taken place mainly in governmental and European contexts and are most suited to Member State government representatives and pan-European health and eHealth organisations.

Overall – as was planned at the project outset – eHealth ERA's dissemination activities have reached both closely targeted and more broad audiences. eHealth ERA has contributed to greater European, and even international, knowledge about and awareness of eHealth issues. Of highest importance are today's eHealth RTD, eHealth strategy, and the implementation activities that are both developing and changing rapidly all across Europe.

Like housekeeping, data collection is ongoing and never finished. As a consequence, eHealth ERA's reports, its European eHealth priorities and strategies handbook – and the database of national eHealth documents that results from all of this –will soon be outdated or are even, to some extent already, outdated even at the end of the project (even when the data has been collated within the last twelve months of the project's duration). How valuable it could be for European policy-makers and national health authorities, and for all other stakeholders involved in eHealth, to maintain an ongoing, constantly updated, database of eHealth research and eHealth policy documents.

## 9 Summary and Outlook

The concerted twenty-seven month period of work of the eHealth ERA coordination action has permitted considerable move towards greater consolidation of thinking and acting on the part of the European Member States, and the closeness and confirmation of their work with the EC particularly in relation to the DG on Information Society and Media.

As a result of this progressive set of activities, the eHealth ERA presents in summary three sets of analysis. They are:

- an overview of the substantial, main accomplishments of the coordination action
- a succinct overview of the ways in which the coordination action could have enhanced its activities, and
- the outlook for both eHealth RTD and eHealth policy and deployment in Europe.

### 9.1 Summary

#### Final outputs

All of the anticipated deliverables have been prepared, completed, and submitted to the EC as of September 2007 in time for the coordination action's final technical review. To complete eleven deliverables were an ambitious goal for such a coordination action within such a concise time-period, but eventually only four were slightly delayed (in each case, by a month or two) (the formation of the Coordination Committee, the European eHealth Policy report ('eHealth priorities and strategies in European countries'), the Coordination Committee decision on the two Priority Topic Clusters, and the completion of the final report. These delays are either, in the case of the more classic deliverables, due to the considerable amount of work involved in the manuscripts concerned and, in the case of the Coordination Committee, the need to await formal meetings which had been postponed. The final eHealth ERA outputs, with their appropriate metrics:

- The establishment of a fully functioning Coordination Committee (achieved month 6)
- The launch of a public eHealth strategies and RTD web site on national eHealth programmes, activities and accomplishments (achieved month 4)
- The completion of an appropriate conceptual framework and information gathering instruments (achieved month 7)
- A European eHealth Policy Report, that presents a structured overview of European eHealth initiatives and roadmaps, synthesises topics with priorities common to multiple Member States, and covers information from all Member States and participating countries (achieved month 23)<sup>50</sup>
- Publication of project knowledge base on the project website (achieved month 23)
- Coordination Committee decision on priority Topic Clusters (achieved month 26)
- Report on Topic Cluster One detailing strategic opportunities for joint activities of Member States (achieved month 22)

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<sup>50</sup> To the extent that such information exists and the national authorities submit it.

- Identification of national institutional structures and connections (from all participating countries)<sup>51</sup> essential to achieve a high degree of cross-Union eHealth innovation-oriented cooperation (achieved month 25)
- Report on Topic Cluster Two detailing strategic opportunities for joint activities of Member States (achieved month 23)
- Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis (achieved month 26)
- Final report on strategic opportunities and action plan for joint activities in eHealth (achieved month 28).

Besides these official deliverables, we wish to emphasise the high public profile achieved by eHealth ERA, its production of the eHealth priorities and strategies in Europe booklet (which was not originally anticipated, but which has found a warm welcome throughout Europe) and its associated database, which the project is now seeking to ensure is even more actively used and exploited, and the role that the project has planned alongside other more formal Committees such as the i2010 subgroup on eHealth, the expert group on eHealth interoperability, and the various stakeholders' groups (both industry and users), and obviously alongside the EC, in building steadily the momentum towards a European eHealth Area. Good relations in this domain were built up with both DG Information Society and Media (the DG to which the project is responsible) and DG Health and Consumer Affairs (by which it was on occasions asked to run and lead workshops).

## Reflections

Given its limited time, budget, and other resources, and considering its comprehensive ambitions, the eHealth ERA achieved a considerable amount over its twenty-seven month period of activity. Highest on the list were the implicit rewards of working in some close co-ordination with representatives of the Member States and of the EC, in ways in which traditional RTD projects do not often have the opportunity. Given the high profile of the coordination action, this collaboration was at times, however, put under pressure (particularly, for example, in the time leading up to the formation of the Coordination Committee whose structure was eventually considerably different from that originally perceived, making decisions about the two Priority Topic Clusters, and producing in due time the eHealth priorities and strategies report.

Ensuring the accuracy, quality, and validity of information produced on the status of the Member States, both in terms of their eHealth RTD and also their eHealth policy, deployment, and implementation was also a constant challenge. The ideal solution appeared to be the use of country-specific correspondents to draft documentation which was then vetted by the Member States representatives themselves. Currently, Member States do not appear (although this has not been calculated quantitatively) to allot sufficient resources to the coordinating role of their representatives vis-à-vis the European level and other Member States. Many of the country-specific representatives are under great pressure to perform their day-to-day roles. This pressure may change, but often does not, when a country takes part in the triad of countries who are in the process of taking up, running, and following up from the Union presidency.

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<sup>51</sup> To the extent that such structures exist and the national authorities submit this information.

In terms of process, the clustering of geographic areas of Member States to the small number of core partners, while a pragmatic approach, was perhaps not the optimum solution. Ideally, each Member State would be in a position to resource fully not only its eHealth activities but, moreover, its commitment to coordinating and liaising with not only the EC but also its other European partners across the board.

Today's challenge remains the member States' need to continue to co-ordinate and collaborate on their next major, joint, shared and structured activities, and not only those we are most immediate – such as the large scale pilot, the thematic network, and the eHealth 2008 conference – but also the longer-term activities implicit until 2010 and beyond, in the eHealth action plan, the activities till 2015 laid out in the draft Recommendation on eHealth interoperability, and the middle- and longer-term RTD activities embedded in FP7, and whatever the next research future is following that activity.

## **9.2 Outlook**

This final overview of the key achievements and findings of the eHealth ERA coordination action permits an outlook on the next future of eHealth in both the field of RTD and of deployment/implementation.

These two fields are treated separately, with their two core contemporary messages, even though it is very clear that both are linked intimately and perform as a form of virtuous circle. Each aspects informs the other. As was the case in the fifteen years of eHealth co-financed research that led to the eventual formulation of the eHealth action plan and solid growth of eHealth throughout Europe – the various elements of scientific development, expressed in both basic research and applied research, influence policy development but over a long-term horizon. Likewise, what is happening on the ground in eHealth deployment may influence seriously, through a sound understanding of user requirements and needs, future eHealth RTD developments.

The two elements have an implicit synergy, which is of considerable benefit to the accomplishments and achievements of both. To separate the two elements would be disadvantageous. This needs to be borne in mind, even as the two domains are analysed separately in this document for purposes of clarity and simplicity.

### **9.2.1 eHealth is an accumulating science, and many other sciences accrue to it**

The main messages which have emerged from the research overview of eHealth in Europe are the following: firstly, that eHealth is an overarching or accumulating science, and that there are many other forms of science which fit comfortably under its umbrella.

#### **Mapping and roadmapping**

In these terms, it is therefore of rapid importance for eHealth RTD to assert its umbrella role, and to undertake a mapping and clustering exercise of the eHealth RTD community of research activists and champions. This would permit the development of vibrant, new, research communities in the eHealth RTD field and the lead to new influences emerging in innovative, fresh, bodies of knowledge).

In combination with this mapping or landscaping activity, roadmapping should take place not only of an eHealth RTD area but also as an inherent link of the outcomes of this coordination action to other roadmaps that have emerged or are emerging from such studies and support actions as RIDE, SHARE, Symbiotic, SemanticHealth, and so on.

### **Making more concrete steps towards the eHealth RTD ERA**

It is also a sound, and fair, aim to take on the challenge of consolidating the framework so as to build a European-wide eHealth RTD (a 'European eHealth RTD area'). It is suggested that this can be done through the following set of ten activities which have already been explored in some detail in this final report:

- Building political commitment to findings of initiatives already undertaken
- Developing a strategic European view of a European eHealth RTD area
- Undertaking a roadmapping exercise so as to create a European eHealth RTD Area
- Joining forces among Member States across Europe, and internationally
- Facilitating a clustering approach among Member States
- Facilitating partnering at the national level(s)
- Identifying core RTD stakeholders at the national level
- Ensuring appropriate funding
- Continuing with evaluation and the assessment of progress
- Undertaking further studies on how eHealth RTD is best done.

In research terms, further studies may be required in a number of areas that involve a more detailed overall assessment field; the types of ministries involved in eHealth RTD, comparisons with European-wide research undertaken on eHealth in the 4FP, 5FP, and 6FP; the ranges of stakeholder involvement; various geographic and regional models of eHealth RTD support, and eHealth RTD classificatory systems or schemes.

### **Proposed activities for 2008**

An initial step in both of these directions could be to consider a set of brainstorming activities that could be handled appropriately within the context of the next high-level eHealth conference to be held in Porto Roz in Slovenia in 6-8 May, 2008. Clearly, the community of eHealth RTD researchers must already start to formulate their expectations and best concepts for this eHealth RTD area and, more pragmatically, for the next steps in the journey of achievements in 7FP eHealth RTD-related initiatives.

#### **9.2.2 Joining together, working together, measuring together**

The eHealth ERA can be seen to have fulfilled its challenging role of enabling Member States to 'join together', by providing them and the EC with a coordination mechanism. This joining together that has occurred *en route* to the formulation of a European eHealth Area, which may particularly focus on eHealth in terms of implementation and deployment.

An interpretation of the eHealth Conference 2007 motto and declaration will enable a shift uniquely from 'working together' to, moreover, 'joining together, working together, measuring together'.

In terms of furthering eHealth deployment in Europe, the eHealth ERA coordination action permits several conclusions for a joint view of four areas: eHealth concepts, eHealth deployment, eHealth users and their contexts of the use of eHealth, and eHealth management and research.

These observations are considered to gel with, and to be complementary to, many of the concurrent activities taking place in, for example, the eHealth action plan latter stages 2007-2010, the proposed CIP large-scale pilot, the longer-term proposed recommended activities on eHealth interoperability, the Lead Market Initiative on eHealth, and various parallel considerations being given in DG Health and Consumer Affairs to key areas for concentration on eHealth. Finally, last but not least, other ongoing possibilities offered by the study instrument as part and parcel of future CIP programme activities in the years 2008-2009 should not be ruled out.

The core emphasis here is on a progression from 'joining together' to the idea of 'working together'. This set of proposals are laid out below:

### **Joint view of European eHealth concepts**

1) Joint minimum definitions of the thematic areas and related concepts (e.g. patient empowerment and patient summaries) should be created.

### **Joint view of European eHealth deployment**

2) Jointly defined target activities for cross-country deployment should be generated for different sectors using existing experiences and use cases, national objectives and studies on stakeholder needs and requirements. Challenges regarding cross-border care quality and cost should also be resolved. Challenges regarding cross-border care quality and cost should also be resolved.

3) In deploying the jointly defined target areas, a shift in emphasis from techno-centric development to co-construction of work, client and information processes and organisation of services, entailing stakeholder participation, should be encouraged. Due to differences in the health service delivery systems and their regulation in different Member States, special attention should be paid to searching for commonalities in the work, information and client processes as well as the organisation of services.

4) Common technological issues that have already been identified, including security, management of registries and repositories, mechanisms for feeding and accessing data and certification, should be worked on further.

### **Joint view of European eHealth users and contexts of use**

5) Attention should be paid to equal access, inclusion, stakeholder involvement and participation issues in order to enhance the value of solutions for key stakeholders and thereby facilitate wider adoption and acceptance of eHealth solutions.

6) Users' competence and motivation to deploy eSolutions (for patient empowerment or patient summaries) as well as producers' competence to develop acceptable solutions should be increased through education and training.

### **Joint view of European eHealth management and research**

7) National eHealth strategies and roadmaps should be further developed to operationalise the objectives and activities, milestones and timelines to enhance the collaboration of countries that have similar targets and timelines.

8) The Member State objectives, evidence on the use cases, cross-border activities and users' needs and requirements should be collected and analysed to inform decision-making about and management of joint eHealth activities.

9) Management of information on current situations, trends, objectives and progress should be more public and transparent. It could be used as the basis for benchmarking and of planning of collaboration.

10) Apart from the issues mentioned above, research should also be conducted on evidence of cost benefits and impacts of eHealth for different stakeholders, policies and legislation.

As a result of this larger overview of the possibilities, the eHealth ERA coordination action therefore considers that four particular areas require more in-depth further exploration:

**Process:** These various activities will help the Member States to prepare for next future stage of eHealth deployment; in this light, a mechanism for supporting all of the 27 countries on eHealth should be considered. For example, it could reflect the notion of an 'open meeting place' 'forum' or 'agora') that ensures the representation of all 27 Member States and supports them directly in their endeavours. This notion provides a link to one of the original concepts of the eHealth action plan, planned for 2005, which was to constitute a high-level forum. While this concept is conceived as having been absorbed in the usual high-level pre-meetings and panels held in the context of the annual high-level eHealth conferences, this flexible solution also leaves room to consider the formation of a not-for-profit association or group which might take up the role of facilitating regular meetings and workshops to support the Member States.

### **Procurement and co-procurement:**

In a pro-active attempt to ensure that eHealth in terms of very practical applications and technologies can be taken up in the widest possible range of European Member States, the notion of appropriate guidelines for procurement should be considered. Sources for relevant ideas may be found in the EC's Lead Market Initiative report, as related to eHealth, which is due for official publication in autumn 2007. Indeed, eHealth should not only be procured independently in different Member States according to the highest standards and criteria, but also collectively, and possibly – for some of the smallest Member States – particularly when they are located in similar geographic areas – might also consider co-procurement of ICT applications, services, and technologies.

**Measurement:**

eHealth ERA particularly embraces the ideas of Member States not only 'working together' but also 'measuring together'. Information collation was one of the first sets of activities for the eHealth ERA. Not only should there now be a regular updating of the individual Member States' activities on eHealth, and particularly their priorities and strategies, but there should be a shift from the notion of pure collation of countrywide materials to a 'compare and contrast', benchmarking, or scorecards model. The eventual purpose behind such an activity would be for Member States to bring themselves into alignment in terms of their eHealth activities (while also focusing on the importance of their national or regional definition of eHealth), to learn and gain from each others' experiences, and to aim all together for the highest possible level of eHealth provision and health service delivery through eHealth.

**Publicity and partnership-building:**

The increasing sophistication of Web-based technologies permits both an ability to present information, to offer publicity, but also – increasingly – to build communities and partnerships. Despite the end of the eHealth ERA coordination action in June 2007, it is suggested that the present eHealth ERA findings should be continued to be offered as a general, public, resource. Therefore, the project coordinator is currently exploring a possible merging of the data with the Good eHealth study in combination with the ePractice activity.

In combination with a high-quality web presence that seeks to build a community of people actively interested in the deployment of eHealth and eHealth policy, consideration could also be given to the publishing of a high-quality publication, that is well-written and well-targeted, with good content and excellent opportunities for advertising support on the part of industry, health authorities, and insurers.

**Note:**

These literature sources need be combined with the appropriate endnotes/footnotes to create a comprehensive list of citations.

**Literature sources**

European Commission (2006) *Information Society and Health: Linking European Policies*, Luxembourg, Luxembourg, 19 October 2006. See <http://ec.europa.eu/information-society/activities/policy/link/>

Iakovidis, I., Dour, O.L., Karp, P. (2007) 'Biomedical Engineering and eHealth in Europe - Outcomes and Challenges of Past and Current EU Research Programs', *Engineering in Medicine and Biology Magazine, IEEE*, 26 (3), pp26-28, May-June

SemanticHealth Deliverable, 1.1, p22

**eHealth ERA Deliverables specifically referenced**

eHealth ERA: Draft Framework Report, August 2005

eHealth ERA: D2.3 Report on Priority Topic Cluster One and recommendations, revised version, 15 February 2007

eHealth ERA: D2.5 Report on Priority Topic Cluster 2 and recommendations – Patient Empowerment, revised version, 31 March 2007

eHealth ERA: Towards a joint view of the European eHealth priorities – a SWOT analysis of Patient Empowerment and Patient Summary activities in Europe, version 0.5, 24 July 2007

eHealth ERA: Dissemination Report, version 0.6, 17 July 2007

## Annex 1: Countries which at proposal stage agreed to participate in the Coordination Committee (national authorities)

Name of national authority	Country	Status of commitment
Federal Ministry of Health and Women	Austria	Official letter
FOD Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu / SPF Santé publique, Sécurité de la Chaîne alimentaire et Environnement	Belgium	Other
Ministry of Health	Bulgaria	Official letter
National Institute of Public Health	Czech Republic	Official letter
Ministry of Health of Cyprus	Cyprus	Official letter
Ministry of the Interior and Health	Denmark	official letter
Ministry of Social Affairs	Estonia	e-mail
Ministry of Social Affairs and Health	Finland	official letter
Ministère de la Santé et de la Protection Sociale	France	e-mail
Federal Ministry of Health and Social Security ( <i>Chair</i> )	Germany	official letter
Ministry of Health and Social Solidarity	Greece	official letter
Ministry of Health, Social and Family Affairs	Hungary	official letter
Ministry of Health and Social Security	Iceland	other
Department of Health and Children	Ireland	official letter
Ministero della Salute	Italy	official letter
Ministry of Health of the Republic of Lithuania	Lithuania	official letter
Ministère de la Santé	Luxembourg	e-mail
Ministry of Industry, Investment and IT	Malta	e-mail
Ministry of Health, Welfare and Sports	Netherlands	official letter
Ministry of Scientific Research and Computer Sciences	Poland	official letter
Ministerio da Saúde	Portugal	official letter
Ministry of Health	Romania	official letter
Ministry of Health	Slovak Republic	other
Ministry of Health	Slovenia	other
Ministerio de Sanidad y Consumo	Spain	official letter
Ministry of Health and Social Affairs	Sweden	official letter
Swiss Medical Association	Switzerland	official letter
The Republic of Turkey Ministry of Health	Turkey	official letter
Department of Trade and Industry / EPRSC	United Kingdom	consortium member

## Annex 2: Analysis of eHealth terminology

Three sets of definitions were used to support the eHealth ERA's analysis of eHealth terminology. These were the types of telemedicine information (SATS), "medical informatics scientific content map" endorsed by the International Medical Informatics Association (which dates from 2002), and These three sets of information are included here in their totality.

### Types of telemedicine information (SATS)

The study on telemedicine distinguishes "types of information transmitted for telemedicine applications", and within these

- the "mode" (asynchronous, (iso)synchronous)
- the "type of information/communication" such as "patient/vital data" and "video images"
- the "application" giving examples such as "EPR", "monitoring of blood pressure" and specifying file size in bytes or transmission rate in bytes per second
- the "typical network transfer mode" e.g. "PSTN", "CATV"
- "access & peripheral equipment" such as "PACS workstation" "PC".

The approach focuses strongly on the telecommunications aspects of an eHealth application.

The terms used in the source table were allocated to the emerging concepts of the eHealth/ICT sub-framework, the healthcare domain (health system needs), general domain, and other domains, as follows:

General ICT Systems

General ICT Systems - networks

World Wide Web

PSTN

ISDN

GSM

CATV

Mobile network

Leased line

General ICT Systems - hardware/software components

PC/Modem

Sound card/microphone

WebTV

Mobile phone

WAP phone

Flatbed scanner  
Document camera  
Commercial videoconferencing equipment  
Computer-based desktop videoconferencing units;  
Videophones;  
Portable videoconferencing systems;  
Set-Top videoconferencing systems  
Interactive video room systems  
Video display unit  
PACS workstation  
PACS viewers  
Digital microscope  
Peripheral devices  
General ICT Systems - other  
Real-time  
Asynchronous  
Isochronous  
Pre-recorded  
Store-and-forward  
e-Mail  
General ICT Systems - information types  
Video images  
Still images  
Healthcare ICT  
Healthcare ICT - hardware/software components  
Blood pressure monitors  
TeleECGs,  
Transtelephonic EEGs  
Digital dermascopes  
ECG devices  
EEG devices  
Electronic stethoscopes  
Tele-ophthalmology systems  
Tele-ophthalmoscopes  
Specialised telemedicine “rollabout units”;

Healthcare ICT - information types

Patient data

Vital data

Electronic Patient Record (EPR)

Electrocardiography (ECG) recording

Electroencephalography (EEG) recording

Dermatology image

Pathology image

X-ray Radiographs

Ultrasound image

CT / MR scan

Computed radiograph

Digital radiograph

Cardiac & pulmonary sounds

Healthcare domain

Healthcare activities and purposes

Monitoring of weight

Monitoring of temperature

Monitoring of blood pressure

Consultation

Surgery

Healthcare knowledge domains

Psychiatry

Ophthalmology

General domain

General activities and purposes

Continuing Education

Education

### **The International Medical Informatics Association medical informatics scientific content map**

The "medical informatics scientific content map" endorsed by the International Medical Informatics Association in 2002 outlines six domains of scientific content:

- Applied technology - including "algorithms", "human genome related", "human interfaces", "cryptology"

- Information technology infrastructure - including "chip cards in healthcare", "networks", "interfaces", "security"
- Data-infrastructure related including "data protection"
- Applications and products including "knowledge-based systems"
- Human-organisational including "IT economics", "security", "unique identifiers" "human-computer interface"
- Education and knowledge including "cognitive learning" "e-business" "knowledge bases"

The terms used in the source table were allocated to the emerging concepts of the eHealth/ICT sub-framework, the healthcare domain (health system needs), general domain, and other domains, as follows:

General ICT Systems

General ICT Systems - terminology

Classification

Coding systems

Concept representation-preservation

Syntax

Language representation

Lexicons

Linguistics

Indexing

Nomenclatures

Terminology-vocabulary

Thesaurus tools

General ICT Systems - networks

Networks

General ICT Systems - hardware/software components

Chip cards

Interfaces

Human interface

User interfaces

User-computer interface

Pen based interfaces

General ICT Systems - other

Algorithms

Boolean logic

Mathematical models

Knowledge bases

Knowledge management

Knowledge based systems

Neural networks

Expert systems

Decision support

Pattern recognition

Digital libraries

Archival-repository system

Distributed systems

Event-based systems

Speech recognition

Image processing

Data analysis-extraction tools

Unique identifiers

Healthcare ICT

Medical records - EPR-CPR-EMR

Evidence based guidelines

Health professional workstations

Laboratory data

Hospital information systems

Healthcare/ICT knowledge domains

Bioinformatics

Economics of IT

Cryptology

Ethics

Security

Systems architecture

Anaesthesia, Behavioural, Cardio/Thoracic, Cardiovascular, Dentistry, Dermatology, Emergency Medicine, Environmental Health, Gastroenterology, Human Genetics, Internal Medicine, Neurosurgery, Nursing, Obstetrics & Gynaecology, Ophthalmology, Orthopaedics, Pathology, Paediatrics, Pharmacy, Primary Care, Psychiatry, Radiology, Surgery, Urology

General ICT Other

General ICT - activities and purposes

Implementation-deployment  
Diffusion of IT  
Human Factors  
Authentication  
Image processing  
Data acquisition-data capture  
Data entry  
Data policies  
Data protection  
Database design  
Modeling  
Information management- dissemination  
Online/distance education  
General ICT - legislation, regulation and standards  
Standards  
Healthcare domain  
Healthcare activities and purposes  
Biosignal processing  
Clinical trials  
Assessment  
Surgery  
Outcomes research and measurement  
Patient identification  
Health/medical informatics education  
Patient monitoring  
Disease management  
Epidemiological research  
Health services research  
Health Information Systems management  
Healthcare valued outcomes/benefits  
Compliance  
Healthcare - other phenomena  
Human genome  
Other domains  
Other activities and purposes - Education

Cognitive learning  
Instruction  
Training  
Consumer education  
Continuing education  
Learning models  
Other activities and purposes - organisations and work  
Collaboration  
Operations/resource management  
Quality management  
Supply chain  
Legal issues, implementing national laws  
Management  
Managing change  
Needs assessment  
Organisational redesign processes  
Organisational transformation  
Planning  
Project management  
Other activities & purposes - Other  
Cognitive tasks  
Communication  
Evaluation  
Policy issues  
Strategic plans  
Privacy  
Security  
Bibliographic  
Biostatistics

### **The Pagliari collection of eHealth descriptors**

Pagliari et al (2005) carried out a brainstorming exercise at the outset of their study to generate descriptors relevant to eHealth, addressing questions such as:

- What issues currently dominate eHealth?
- What is going on in eHealth?

- What emerging technologies are likely to impact on healthcare?
- How does research inform eHealth?
- How do developments in eHealth inform research?

The terms used in the source table were allocated to emerging concepts in what was called the eHealth/ICT sub-framework, the healthcare domain (health system needs), general domain, and other domains, as follows:

General ICT Systems

Terminologies,

Web browsers

Digital TV

Mobile phone

Smart phone

Personal digital assistant (PDA)

Web mail client, other mail client

Satellite

In-building wireless networks

Mobile networks

Decision-support

Decision aid

The Web

The Internet

Database

Information

Communication

Healthcare ICT

Electronic Patient/Health Records (EPR, EHR)

Clinical coding

Healthcare/ICT knowledge domains

Bioinformatics

Epidemiology.

Knowledge management

Systems analysis

Communication network modelling

Organizational development

Nanotechnology

Implantable devices

Virtual and mixed reality

ICT system design methodologies (user involvement in product conception, design and testing; iterative development; needs and requirements assessment; usability research)

ICT system takeup phenomena (people and organisational factors, acceptability, resistance to change, implementation strategies)

Healthcare domain

Healthcare people roles

Citizen, consumer, patient

Clinician, practitioner, clinical management

Relative location: remote, co-located

People pairs: inter-professional, clinician-patient

Healthcare - other phenomena - diseases

Diabetes

Healthcare purposes & activities

Screening

Therapeutic intervention

Surgery

Consultation

Disease monitoring

Prescription

Referral

Discharge information

Clinical information

Second opinion

Laboratory test request

Test results report

Healthcare valued outcomes / benefits

Clinical outcomes

Data protection/security

Patient access

Patient control

Equitable access

Facilitate work of other public services (e.g., social work, police)

Confidentiality  
General domain  
General purposes & activities  
Appointment booking  
Appointment reminder  
General valued outcomes / benefits  
Outcomes  
Cost-effectiveness  
General content  
Prompt  
Reminder  
Guideline  
Booking  
Other domains  
Other purposes & activities  
Evaluation, outcome assessment  
Education, teaching  
Billing  
Tracking  
Audit  
Quality assessment  
Policy-making  
Research

## Annex 3: ICT and eHealth sub-framework and glossary

The following lists include a preliminary typology of actors and roles that are relevant in health system activities, and some other potentially useful concepts and preliminary understandings of relevant terms. The listing included healthcare services, healthcare providers, healthcarer roles, other terms and concepts, and ICT terms and concepts. These understandings are intended to be useful in developing a consistent project vocabulary and, also eventually, a consistent eHealth vocabulary.

### Healthcare services

**eHealth service:** a healthcare service using at least one ICT system.

**Healthcare service:** one or more organisational processes designed to maintain and/or improve the health of one or more citizens

**Healthcare process:** an organisational process contributing to a healthcare service, including diagnosis, treatment, rehabilitation, monitoring, follow-up, prevention, health insurance administration

**Healthcare activity:** activity forming part of a healthcare process such as: taking vital signs, asking questions of patients, changing bandages, examining biopsy tissues, taking radiology images, selling medication, taking payment, reimbursing costs, changing bed-linen, transporting patients. Some activities require direct interaction with one or more individual patients, their tissues and fluids or their clinical data, these are *specific* healthcare activities, i.e. are specific to a patient or set of patients who is / are the target of the service (excluding mock diagnosis for educational purposes for instance) and to a specific illness or other specific health impairment.

**Healthcare** is one or more healthcare services. The term is also used more loosely to include informal and self-help and commercial services designed for the same purpose.

**Healthcare provider organisation:** an organisation or part of such engaging in healthcare activities. A self-employed doctor or other person is an organisation in this sense.

**Healthcare professional:** an employee of a healthcare provider organisation

**Healthcare personnel:** healthcare professionals

A **health service** (deprecated) is a set of healthcare services under common management or regulation.

### Healthcare providers

**Healthcare organisations** (organisations employing personnel providing specific healthcare services to patients): Health centres, hospitals, emergency services, imaging centres, laboratories, pharmacies, doctor, dentist, midwife, nurse, chiroprapist,

**Public health bodies** (epidemiology data gatherers - for health information see healthcare information providers): DG Sanco, WHO, Ministries of health, local government

**Healthcare information providers** (organisations and individuals authoring and/or publishing electronically or on paper information about healthcare for citizens, patients and healthcare personnel) include: universities and colleges, publishers, authors, editors, web-site providers

**Healthcare insurers** (Bodies acting to insure and compensate for or reimburse costs for individual patients) public health insurances, private health insurances, national health services

### **Healthcare personnel**

**Other healthcare personnel:** dentists, midwives, paramedics...

**Doctors** includes those individual roles in the provision of specific healthcare services usually requiring a medical doctorate including physicians, gynaecologists, surgeons, oncologists, anaesthetists, paediatricians...

**Nurses:** individuals with nursing qualifications whether working as community nurses, in doctors' surgeries or in hospitals.

**Healthcare ancillary staff:** healthcare location managers and administrators, porters, cleaning staff

### **Other actors and roles**

**Informal carers** (private citizens not necessarily formally educated in healthcare providing specific healthcare services to one or more patients)

**Self-helping citizens:** Patients and other citizens operating in the role of healthcare personnel (determining medication, monitoring vital signs, monitoring for signs of illness...)

**Patients** (individual citizens having suffered an injury or attack of an illness and before that illness or injury is fully cured or more generally: citizens having suffered a health-threatening event and before the impact of that event has been eliminated / has become irrelevant)

**Healthcare suppliers** (organisations trading in goods and services which enable provision of specific healthcare services but are not themselves specific healthcare services): pharmaceutical companies, providers of medical equipment, ICT suppliers, pharmacies

**Healthcare policymakers:** ministries of health, local authorities, municipalities, World Health Organisation, DG SANCO

### **Other terms and concepts**

**Healthcare location:** (Work locations of healthcare personnel providing specific healthcare services) include: health centres, dentists' surgeries, hospitals, doctor's surgeries, emergency service vehicles, imaging facilities, laboratory facilities, pharmacies, chiropract, patients' homes, other locations.

**Health-threatening event:** event which leads to ill-health or to an increase in the risk of such including acute infection, injury, trauma, accident, onset of chronic condition, pregnancy.

### **eHealth ICT terms**

**eHealth application:** an eHealth service (synonym)

**eHealth <ICT system> application:** an eHealth service using the named ICT system.

An **eHealth technology component:** an ICT system which is part of an eHealth service. Synonyms: eHealth ICT, healthcare ICT

**eHealth technology:** any ICT system or systems which are part of an eHealth service or services.

An **eHealth system:** an ICT system used in one or more eHealth services.

**ICT system:** any collection of one or more items of software, hardware, network, data structure, communications protocol and/or data which are designed to be used together for a purpose

An **ICT component:** an ICT system which is part of a larger ICT system.

### **General terms**

**Organisational process:** a series of paid or charitable work activities by individuals in organisations designed for a purpose.

## Annex 4 – Acronyms and abbreviations

ACM .....	Access, Competence, Motivation (as in 'model')
BMGS .....	German Federal Ministry of Health (English translation of the German ..... equivalent title)
CIP .....	Competitive and Innovation Programme
ERA .....	European Research Area
ER(I)A .....	European Research (and Innovation) Area
GDP .....	Gross Domestic Product
GP.....	General Practitioner
EPR .....	Electronic Patient Record
EHR .....	Electronic Health Record
EU.....	European Union
ICT .....	Information and Communication Technology
IPPA.....	Integrated Programme Portfolio Analysis
IPTS.....	Institute for Prospective Technology Studies
IST .....	Information Society Technologies
ISTAG .....	Information Society Technologies Advisory Group
RTD .....	Research and Technology Development
PSP.....	Policy Support Programme
SATs .....	Space and Advanced Telecommunications
WP.....	Work Programme
WT .....	Work Task
US.....	United States of America
5FP, 6FP.....	Fifth Framework Programme, Sixth Framework Programme,
7FP .....	Seventh Framework Programme

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