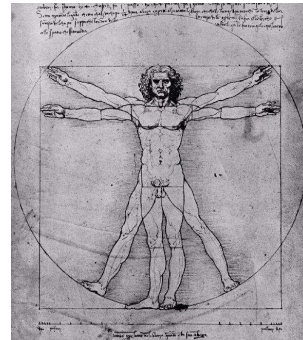


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e-health in the European Union: an assessment of its socio-political foundations

Charalampos Ipektsidis

Maastricht University/Namur Notre-Dame de la Paix University
International Masters Programme in Science, Technology and Society
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Supervisors: Prof. Dr. Claire Lobet-Maris,
Prof. Dr. Philippe Goujon

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PREFACE

Hereby, I would like to take the opportunity to thank a number of people who have contributed to this thesis. I would like to thank my supervisors Prof. Dr. Claire Lobet-Maris, and Prof. Dr. Philippe Goujon, that helped me with their patience, advices, and support. I would like to thank them moreover for their critical remarks, which helped me improve my work considerably. Additionally, I would like to thanks Ms. Diane Whitehouse of the Directorate-General Information Society Unit H1 - ICT for Health for the interesting insights she provided me in relation to the European Commissions policy about the subject.

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SUMMARY

In the last years, the discussion about the future of healthcare systems has revived. It is nowadays acknowledged that health care is a major issue for a country's welfare status in all levels, either economically and socially, or demographically. We live in an age that the health care sector demands on reducing costs and simultaneously on improving his quality and access to all. The challenges that the health care systems have to face include the rising demand for health and social services, the management of huge amounts of health information that need to be available securely, accessibly, and in a timely manner at the point of need and finally the need to provide the best possible healthcare under limited budgetary conditions.

The appearance of information technology into society, and consequently into healthcare, has led to the fact that the term e-health is increasingly used and is promoted as a solution to some of the above-mentioned problems. Interestingly enough, although the problems of the healthcare systems are acknowledged and also the introduction of technology is thought to be the solution to the problems; mere attention has been directed to investigating the development of e-health in the European Union and the premises on which this development took place.

Nonetheless, examining how the concept has changed is important as it helps us to understand the general developments in the field and it gives an overview on which premises the future policies in the field could be based on. Thus, this thesis discusses the development of e-health in Europe and the premises on which is it based. Consequently, it examines among others, how e-health is developed in a policy level, which are the actors that can be identified in the policy level, and it examines how this policy level is implemented in reality through some best cases. The thesis tries, by focusing in the European area, to answer questions as: who are acknowledged as relevant actors of e-health both in a policy level and in a real life case level? Thus, a relevant question, which is discussed, is if the patients for whom the technology is intended, involved.

Furthermore, in an undersized abstract/theoretical level, the thesis discusses the changes in the concepts of health as a change in power and examines the development of e-health as part of a more systemic change. This more general change highlights the movement from a predominantly centralised system towards a more individualised/personalised system. Additionally, in trying to explain this change, the thesis introduces the concept of governmentality, which is very important as a general question that arises in all aspects of our

life when we use new information technologies is: How in a state so complex can we have a democratic control of so complicated systems?

Keywords: European Union, e-health, policy papers, best cases, citizen,

1 INTRODUCTION

1.1 Background

Health care is a major issue for a country's welfare status in all levels, either economically and socially, or demographically. We live in an age that the health care sector demands on reducing costs and simultaneously on improving his quality and access to all (OECD, Docteur and Oxley, 2003). The appearance of information technology into society, and consequently into healthcare, has led to the fact that the term e-health is increasingly used. In the last years, a number of pressures in the traditional National Health Systems are emphasising the need for changes. In fact, healthcare systems around the world face major challenges, even if their nature and scale vary significantly between industrialised and developing countries.

In the same time, the knowledge flow in the contemporary society notifies the need for the use of new technologies both for the support of the traditional medicine through local, national and global sharing in practice methods and clinical outcomes and in a second not so apparent level for the empowerment of citizens as self-coordinators of their being.

1.2 Why e-health

The challenges that these new healthcare systems have to face include the rising demand for health and social services, due to an ageing population and higher income and educational levels. As a matter of fact it is expected that by the year 2051, close to 40% of the population of the European Union will be older than 65 years old (Braun, Constantelou, Karounou, Ligtoet, & Burgelman, 2003). Another important fact is the increasing expectations of citizens who want the best care available, and at the same time, to experience a reduction in inequalities in access to good healthcare. Furthermore, there is also the fact of the increasing mobility of patients and health professionals due to the internal market and the freedom of movement of labour, capital, goods, and people.

Additionally to the above and maybe of greater importance, is also the management of huge amounts of health information that need to be available securely, accessibly, and in a timely manner at the point of need, processed efficiently for administrative purposes, and also the need to provide the best possible healthcare under limited budgetary conditions. Finally and a point of emphasis are the difficulties experienced by public authorities in matching

investment in technology with investment in the complex organisational changes needed to exploit its potential. (COM (2004) 356 final)

Nowadays, primary care is considered to be in the forefront of importance as the expertise knowledge is moving downwards, closer to the patient in remote units or at home, as also the citizen-centred healthcare envisages. Thus, Government's strategy of decentralising healthcare delivery is both the realisation of equity of access to specialist services outside the hospital environment but also the need to control the increasing cost of health care and the long waiting lists. From the above, it can be understood that the challenges for the healthcare system are enormous and pressing. In the next section of this chapter, the problem statement of this paper is introduced. This problem statement is based on the development of e-health in the European Union, as e-health is one of the solutions selected to combat the problems of the healthcare system.

1.3 Problem definition, and problem statement

The objective of this thesis is ultimately to identify if the patients are increasingly becoming the focus of attention in the development of e-health. Consequently, the problem statement developed in this paper is the following: *What is the development of e-health in Europe and on which premises is it based?*

Interestingly enough, although the problems of the healthcare system are acknowledged and the introduction of technology is thought to be, based on a technological deterministic logic, the solution to the problems; mere attention has been directed to investigating the development of e-health in the European Union and the premises on which this development took place. Nonetheless, examining how the concept has changed is important as it helps us to understand the general developments in the field and it gives an overview on which premises the future policies in the field could be based on. Consequently, the aim of this thesis is to examine and analyse the development of e-health in the European Union.

As a result, this thesis begins with the discussion of health theories and the role of the society and continues by focusing on e-health as a system and what it brings with it¹. Accordingly, it examines among others, how e-health is developed in a policy level, which are the actors that can be identified in the policy level, and it examines how this policy level is

¹ Although ethics constitutes a major part of the general discussion about the development of e-health it will not be part of the discussion of this thesis

implemented in reality through some best cases. Therefore, the thesis tries, by focusing in the European area, to answer questions as: who are acknowledged as relevant actors of e-health both in a policy level and in a real life case level? Thus, a relevant question, which is among others discussed, is if the patients for whom the technology is intended, involved. Furthermore, in an undersized abstract/theoretical level, the thesis discusses the changes in the concepts of health as a change in power and examines the development of e-health as part of a more systemic change. This more general change highlights the movement from a predominantly centralised system towards a more individualised/personalised system. Additionally, in trying to explain this change, the thesis introduces the concept of governmentality.

In fact, the question of governance is very important as a general question that arises in all aspects of our life when we use new information technologies is: How in a state so complex can we have a democratic control of so complicated systems? How can we ensure that there is more involvement and more openness of the system to the citizens? How can we ensure that a different voice can be listened and taken into account? Nonetheless, although this is a very important point this thesis will only touch upon it.

1.4 Outline

To achieve the research objectives set, the outline of the thesis is presented in the following abstract. The paper after this introduction begins with the second chapter, which provides a historical overview of the changes in the concept of health from the nineteen sixties until the early years of the nineteen nineties. This is done in order to illustrate that the concept of health was not stabilised and in order to demonstrate which concept of health has been predominant before the introduction of e-health. Through this approach, we are able to see the situation before the development of the concept of e-health and to demonstrate on which concept of health the development of e-health discussed in the third chapter has been founded on.

Continuing the fourth chapter of the thesis discusses the development of the policies and the actions of the European Union in the development of e-health. In doing so, it focuses on the roles of the different actors represented both in policy papers and in real life cases. Nonetheless, the focus will be more on patients, as patients are the centre of attention of this thesis. How these e-health initiatives are implemented, in the form of the framework programmes financed by the European Commission, can be observed in the fifth chapter and

progressing in the sixth chapter some selected patient/citizen oriented best cases from the European area are presented. Finally, the conclusion recapitulates the findings.

2 THE EVOLUTION OF THE HEALTH CONCEPT

Preface

In this chapter, the concept of health is presented and analysed with the intention to facilitate as an introduction of the general framework. Additionally, this chapter has also the intention to provide the reader a more thorough overview of how the concept of health has changed over the years. This is very important, as we need to understand the continuum and the framework on which the notion of e-health is founded on, in order to proceed to the next chapter, which will be more specifically about e-health. Consequently, and with the intention to illustrate the interconnection between the changes taking place, first in the concept of health as well as after the introduction of technology in e-health, the thesis is written using a chronological approach.

2.1 The concept of Health and the historical changes

In accordance, this section of the thesis provides an overview of the changes in the concept of health and on its theoretical foundations beginning from the conceptualisation developed in the nineteen sixties until now. This approach is selected mainly in order to illustrate that the concept of health does not remain constant. In fact, a question that this chapter investigates is: can this change be described as an evolution from a more holistic/centralised approach into a more individualised/personalised based approach?

The question that arises here is why is it important, in the context of this thesis, to know how the theory about health has developed? The answer is that is important, for the reason that through this approach the starting point on which e-health is based upon is identified. Thus, we are able to see on which premises, on which general theoretical foundations of the concept of health, the introduction of technology emerges.

Consequently, sections 2.2 and 2.3 will show the changes in the meaning of health, and its connection to society. Subsequently, section 2.4 will introduce the concept of governmentality with the purpose on the one hand of explaining the developments and on the other hand to provide a general framework that can explain what has happened. Continuing section 2.5 will emphasize that health in the last years has been predominantly based on economic rationality and finally the last section of the chapter namely 2.6 will provide a synthesis of the chapter.

2.2 The changes in the meaning of health – Theories of health

This section has as its objective to introduce some of the most influential definitions of health and some of the most important theories about the development of health in Europe, and more generally in western societies. This will facilitate the paper by means of identifying the basic theoretical framework of the concept of health on which also the introduction of e-health in a later phase bases on.

Most people have their own definitions of health and what it means to be healthy. Actually, it is often the case that considerable differences exist among people about what it means to be healthy. Even though personal definitions of health are important to individuals and can vary widely, nevertheless, at a policy and service level, the use of agreed definitions of health assists in providing some commonality and transparency about what is meant by the use of the term. However, this does not denote that definitions of health are stable. On the contrary, they have changed considerably over time.

Fundamentally, the etymological roots of the word health lie in the Old English for “whole” which connotes that at that time a person who was healthy was complete. Nevertheless, the mostly widely accepted and longstanding definition of health is that of the World Health Organisation. In 1946, the World Health Organisation provided the following definition of health. Health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.

According to Seedhouse, (1986) in modern Western societies, several competing theories of health co-exist. The first theory is that health is an “ideal state”. This theory can be linked to the above-mentioned definition of health provided by the WHO in 1946. Nevertheless, taking into account that the theory developed immediately after the Second World War, it can be understood that it made sense at that time since the situation was different from the one we nowadays have. Using this definition today is an end in itself as it does not allow for a dynamic approach to our understanding of health and it presupposes that perfect wellbeing exists in every respect. This means that it views health as being a static state that is controllable and cannot change in a fast manner. As it becomes clear, using such an all-rounding definition is not suitable. Evidently such an approach, that could be characterised as normative, constitutes today a problem as using it presupposes that disease, illness, handicap, and social problems are absent, which of course is far from being the reality.

A second theory that Seedhouse identifies in his works, is this of health as the physical and mental fitness to do socialised daily tasks. It can be stated that this theory is a product of

the emergence of a more community thinking approach, which was developing in the late nineteen sixties. Breaking this definition down results, that from an individual level this connotes having the physical and mental fitness to engage in own self-care activities. On the other side, from a community perspective this implies that the community as social structure is dutiful, generous, caring and protective. In the same manner, Talcott Parsons (1972) states that health is “The state of optimum capacity of an individual for the effective performance of the roles and tasks for which he/she has been socialised”. Thus, based on Parsons this theory could be described as promoting a functionalist perspective.

A third theory is health as a personal strength or ability. This theory emphasizes the role of health as the foundation towards achievement and accentuates a turn into individualism. The theory suggests that health is concerned with physical strength, ability to adapt and cope and individual self-actualisation. According to Dubos health is “...not a state of being (...) it is a process of adaptation to the changing demands of living and the changing meanings we give to life.” (Dubos 1960, cited in Naidoo & Wills (1994) p15) or as he puts it health is “the condition best suited to reach goals that each individual formulates for himself” (Dubos, 1960, p219)

Finally, another approach, and actually the most evidently used in reality in the last years, is health as a commodity that can be bought or given. Fundamentally, this theory, reinforced also by the growth of modern medicine, is the underlying principle behind the current medical theory and practice. If we apply the concept to individual health, this fits “inside the disease model of health as the absence of disease”. In this case, the absence of disease is considered as a state of health. Moreover, if we view this approach within the notion of community, it can be operationalised in the provision of traditional medical and health care services in response to the status of health of individuals and groups within a community, and thus be offered as a commodity (Community health and community nursing, Unit 2). In order to strengthen this point Seedhouse (1986, p.34) states that: “The predominant image which overshadows medicine and the British health service is that health is a commodity. That is something- albeit an amorphous thing- which can be supplied. Equally it is something that can be lost”.

Conversely, all these theories can be said to lead to the actuality that health has become the foundation for achievement of potentials “A person's optimum state of health is equivalent to the state of the set of conditions which fulfil his or her realistic chosen and biological potentials. Some of these conditions are of highest importance for all people. Others are variable dependent upon individual abilities and circumstances” (Seedhouse,

1986). Analyzing this last theory, we can see a change in the perceptions about the role of society in general. In the past, norms were developed by the society in total. Nowadays however, we can identify that norms are derived from the individual. This obviously highlights also a turn of the society in general from a more communitarian to a more individualistic, predominantly auto-normative approach.

Concluding, this section has presented several of the different competing theories of health that can be identified in the western world. All these definitions however show that health is holistic and dynamic. Health is holistic in the sense that it encompasses many different types. It is possible to talk of physical, mental, emotional, social, spiritual and societal health. Furthermore health is dynamic and not static as it shifts and changes through time. Concluding this section, it could be stated, that health in the theoretical framework has moved from a centralised system to a more individualised/personalised one as also the following *significant table*, product of this thesis, shows that summarises the different health theories.

Table 2.1 Health theories and the different approaches

| Health Theories | Approach |
|--|---|
| Health as an “ideal state” | Normative |
| Health as the physical and mental fitness to do socialised daily tasks | Centralised system with a rather top-down (functionalist) approach as community defines the concept of health |
| Health as a personal strength or ability | Change to a more individualistic approach |
| Health as a commodity | Individualistic/personalised approach. Health becomes a commodity |

2.3 How the society is involved. Social systems and change of definitions

Now that we have seen the different theories about health, it is time to see how the society is involved in this and how these changes of the definitions of health based on the different theories of health can be best explained. One of the first thoughts somebody makes while reading these theories is that they represent a gradual change: a change towards a

market based system, as health is gradually becoming a commodity². What is more is that, as this and the following sections of the chapter will show, these theories can be also seen under the prism of changes of relevant power in the healthcare network and the tensions between the different actors.

Returning to the table constructed in the previous section (Table 2.1), it could be in fact stated that what all these theories have in common except from the fact that they are about health is that they acknowledge different levels of power to the individual and show also a change in the direction of power. A change, that can be best described as being from a centralised system by the state towards a more individualised/personalised system. This section basically explains the changes presented in the table under the form of power relations variation.

The society, and, as a part of it, the social movements³ dealing with health, are very important influences, and a major force for change in the larger society and more specifically on our health care system. In point of fact, one of the most prominent features of modern society is the rise of professional authority in general, and in the framework of this subject more specifically of medical authority. This involves laws and regulations regarding how professionals are empowered to make health decisions and to provide care, the determination of, and application of, the knowledge base for medicine, and finally the power of medical authorities to deal with a variety of social problems that may not be primarily medical.

The rise of medical authority is a topic, which has been acknowledged and has been studied by many authors and researchers. Foucault in his book, *The Birth of the Clinic* (1975a; orig. 1963), subtitled “An Archaeology of Medical Perception”, analysed the shift from a premodern medicine based on speculation to a modern medicine based on empiricism and rooted in scientific rationality. Rejecting a history based on the “consciousness of clinicians”, he pursues a study of discourse that seeks to determine ‘the conditions of possibility of medical experience in modern times’ (Foucault 1975a: p. xix). He also examines the historical conditions whereby a scientific discourse of the individual can first emerge (Best and Kellner, 1991).

According to Brown and Zavestoski (2004) medical authority is tied into the broader trend of solidification of scientific authority, in which science plays an increasing role in

² Something to be valued, exchanged, bought and sold.

³ Historically the first examples of social movements organising around health issues date at least back to the Industrial Revolution and the concerns about occupational health. Nevertheless, as the focus of this paper is in the current occurring changes and in the evolvement of e-health the focus of this review will go only back until the 1960’s and in the change that begun at that time in the general landscape around the notion of health

determining and evaluating social priorities. In addition, medical authority has always involved changing alliances between health professionals, the state, companies, scientists and citizens that form the health caring network. For many scholars, authority structures, inside this network, are viewed as an aspect of stating the relevant power the different parts of the network have. As a result, authority is influenced by power relations as also Foucault has highlighted in his works.

In fact, Brown and Zavestoski (2004) have researched in this direction and found that this exists also in the health sector as one would also expect. “In our modern scientized world, science and medicine have become increasingly powerful sources of authority that play a central role in supporting dominant political and socioeconomic systems”. Furthermore, they state that concepts such as “medical social control” (Zola, 1972) and the “medicalization of society” (Conrad, 1992) have demonstrated how health belief systems and the practices of the health care system support and maintain existing class, race and gender inequalities”.

In the same line of thought, May, Allison, Chapple et. al (2004) have also investigated about the rise of medical authority. They have come to the conclusion that from the late nineteen sixties, the doctor-centred model of the clinical encounter faced continuous criticism. This was among others, also a product of the wider cultural and political shifts and tensions in the nineteen sixties, like for example, the famous uprising of the Parisian students in May 1968 and the changes it brought with it. In the field of health, this has worked to undermine both the paternalism and the biomedical reductionism of medical practice. The result of this new approach was that a fundamental change occurred. While until then patients were seen as the passive objects of clinical knowledge and of the procedures, after the wider cultural and political shifts they demanded to be understood and treated as “whole persons”. This is intrinsically a consequence of a political shift that began with the critique of medicalization (Conrad and Schneider, 1980) and extended to include a holistic impulse that connected ill-health with a wider pattern of social relations and contexts (May, 1992). Commenting this change in the context of power structures, it can be stated that this is very important, as for the first time the patients demand to be empowered and that their “local knowledge” is used.

Based on these changes and starting on the nineteen seventies a new approach can be observed. It is the era where some elements of academic medicine began to co-opt both the theoretical positions of the social sciences (Strong 1979a, Stacey 1991), and to attempt to place claim to the much wider vision of ill-health espoused by proponents of a bio-psychosocial model of medicine (Engel, 1977). In the same time, academic practice began to examine the form and content of the consultation much more systematically. The consultation

was about the negotiation of two kinds of expertise: the authoritative general expertise of the doctor (often conceptualised as professional knowledge) and the specific experience of the patient (often conceptualised as lay beliefs).

These changes coincide with the work of Foucault, which illustrates the relationship between knowledge and power and the way these are used in the language of individuals and groups to construct a social reality (Foucault 1976) that reflects and reinforces the power relations that exist and thus characterises power as part of the process of interaction.

2.4 Explaining the changes

As already stated the question of medical authority has been examined by many authors, which came to different results. For some authors in essence this change took place, because within medicine itself, there “was a move towards enrolling the patient into the consultation in ways that reduced the growing strain on the epistemological authority of medical knowledge that seems to have become more evident as a result of wider shifts in its social production and organisation during this period (Lupton, 1994)”⁴. In this framework, the shift to the concepts of patient-centredness, empowerment and satisfaction, as alternatives for quality of care in general practice can be seen not purely as technical moves towards improving the quality of care, but also as ideological moves.

Nevertheless, according to other authors this shift away from the doctor-centred consultation to negotiated consultations was also promoted by specific government policies intended to increase professional accountability and model patients as active consumers of healthcare, able to judge on its content and quality (Moran, 1999). Essentially, these authors state that “science and technocratic decision-making have become an increasingly dominant force in shaping social policy and regulation. Governmental and scientific demands for ‘better science’ in policy-making have become a significant and powerful authority used to support dominant political and socioeconomic systems (Brown and Zavestoski, 2004)”.

This section shows that public health may be conceptualised as a governmental apparatus, as the institution of public health has served as a network of expert advice, embodied in professionals such as doctors and health promoters, who have dispensed wisdom directed at improving individuals’ health through self-regulation. In order to do so, it introduces the concept of governmentality. The concept of governmentality is highly relevant

⁴ May, Allison, Chapple et. al (2004) “Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners’ accounts” *Sociology of Health & Illness* Vol. 26 No. 6 2004

as it “incorporates an analysis of both the coercive and the non-coercive strategies which the state and other institutions urge on individuals for the sake of their own interests, it provides a mean of understanding the social and the political role of public health (Lupton, 1995)”. Furthermore, the concept, as it will become clear later, is a valuable tool in order to understand the developments presented already in table 2.1.

Foucault’s seminal work on governing, which flow from his more well-known work on power, reconceptualised government and governing as practices evident throughout society rather than simply those conducted by the state (Rose and Miller 1992). Government is defined as the ‘conduct of conduct’ rather as regime, institution or apparatus and is as much a practice of bosses, managers, parents and the individual self as one of monarchs, presidents and parliaments (Henman and Dean, 2004). The writings of Foucault have generated a renewed interest among political and social scientists like Gordon (1991), Dean (1999) and Rose (1999) in processes of governing in the modern world.

Foucault, paid particular attention to the way in which certain liberal forms of governmental rationality emerged during the early modern period. In contrast to the traditional approaches of political theorists, who view liberalism and neo-liberalism as limiting the practice of government, governmentality studies focus on how liberalism and neo-liberalism constitute government by other means. “Choice, desire, and aspiration becomes means to governmental ends, and elements to be shaped by governmental programs and practices. In this latter respect, liberalism seeks to govern through individuals by means of shaping their capacities and thus constitutes them as citizens” (Henman and Dean, 2004). Furthermore, many of the studies inspired by Foucault’s work have been influential in mapping and making apparent modern forms of government in which typically neo-liberal forms of rule give rise to indirect methods of governing conduct. In “neo-liberalism, force and coercion are displaced by forms of inducement, incentive mechanisms, persuasion by experts and discipline through surveillance” (Gaby and Henman, 2004). As Nikolas Rose (1999) puts it, individuals are free subjects who choose their forms of behaviour, but their choices are made in settings that have been constructed by a whole barrage of carefully-calculated tactics, such as performance indicators and audits (Rose 1996; Miller and Rose 1997; Power 1997).

Nevertheless, a question that may be posed now is what is the connection between governmentality and health? Although not apparent, the governmentality perspective reveals the governmental relations and practices implicated in health care and highlights how doctors have long been bound up in governmental relations with the state; perhaps since the nineteenth century (Osborne 1993, 351). This shows that in the near past (since the nineteenth

century), the whole health caring network was centralised. Moreover, this approach helps us to see the capillaries of power obscured by this perspective, for instance, by recognising the power of medical knowledge and the ways, it might be used to persuade, classify, normalise and control. As already, noted, the doctor-patient relationship has traditionally been one of considerable power differentials, where the doctor possesses medical knowledge and the patient's knowledge has largely been deemed irrelevant. This has been reinforced, to some extent, with the rapid development of diagnostic technologies where patient disclosure about symptoms is replaced with 'objective' bodily measurements (e.g. x-rays, pathology and genetic tests)⁵.

In the same line of argumentation and in a rather similar approach the movement towards treating health as a commodity can also be best explained through governmentality. As the general framework of policies or better said the "rules of the game" are affected if not promoted by government decisions, we could suppose that this was also the case here. Indeed, there are certain indications that could affirm that this has been the case. One of them actually uses what we have acknowledged as a fact, that government has introduced the scientific and technocratic decision-making in the health system. This approach was founded on considerable power differentials between the different actors, nevertheless was useful in order to be able to centralize the whole construct having in the central role the physician, the doctor et cetera. Additionally, due to the increasing introduction of technology the position of doctors also changes with the result that health becomes a more technical process⁶.

Deriving from this, it could be stated that economic rationalisation is another form of technocratic decision-making. Nonetheless, this time the central role is not played by the physicians and doctors but the state allows the individual to choose his form of behaviour, but in a setting that has been constructed by a whole barrage of carefully calculated tactics, such as performance indicators and audits. Nevertheless, because health becomes a commodity the individual has the possibility to make his choices as the next section will also demonstrate. This inherently allows us to state that health moves from a rather centralised by the state approach into a more individualised, personalised, based approach.

⁵ Technology plays an important role in the development of medical theory as well as clinical practice. The discovery of bacteria, the development of penicillin, and the elaboration of the diagnostic and therapeutic armamentarium have all played an evolutionary role in medicine over the last two centuries. Evans (1991) for instance argues that technology today constitutes the aetiological agents that define disease.

⁶ As Reiser (1978) states the "twentieth-century technology with all its progress had tended to push the human dilemmas of illness out of the doctor's thoughts, and replace them with laboratory facts derived from tests on the patient's". This means that technology nowadays in many cases demonstrates or even directs the path that medical professionals follow.

It is apparent that economic rationalisation brings along with it, considerable control over debates regarding the costs, benefits and potential risks of new technologies and industrial production by deploying scientific experts who work to ensure that battles over policy-making remain scientific, “objective” and effectively separated from the social milieu in which they unfold (Beck 1992). On the other hand, through this economic rationalisation, which will be presented in the next section, other problems arise like if it is ethical to use a strict economic approach in a normative fact like health.

2.5 Economic rationalisation

In order to examine the changes that the economic rationalisation brought about in the concept of health some examples provided by the changes followed in the organisation of hospitals initially in the United States and after a while in Europe will be used. Nonetheless, before presenting it, it is wise to explain in advance, why this subject is important to be highlighted in the frame of this thesis.

The increased focus on economic rationality has resulted into the fact that personal healthcare, which is normative and subjective, is treated as part of a general standardised procedure. Thus, healthcare is under the logic of economic rationality that presupposes that every action done should be accomplished within the structure of certain procedures in order to be efficient and effective. Nevertheless not every illness and every patient is the same and thus there will always be patients and illnesses that will not be acknowledged by the system as they are not quantifiable and thus not part of a system organised under the strict economic rationality. Here the question that arises is about the ethics of using a strict economic approach in a normative fact as health. The problem however is that under a strict economic logic, and with the healthcare system organised traditionally in this manner, no profound ethical solution can be given to such problems⁷.

Now that this inadequacy of treating health as a commodity, and only by means of economic rationality is highlighted, it is time to see what new effects this approach brought about. After the decrease in the supremacy of doctor centred models as a result of the continuous criticism they faced and following a period in which government influence predominated, U.S. hospitals have entered a new era, this of market competition. This era has

⁷ Alternatively others believe that due to the ever-increasing use of information technology the patients that were not adequately served by the traditional healthcare system may benefit. This will be an effect of the changes occurring to the system and in addition from the possibility to use the advances technology brings with, to become more “visible” for the healthcare system

led to an even greater extent to the recession of the medical profession and to an intensification of competition in general.

Managed care, is the major force behind this intensification of competition pressures, which produce the same results as competition in general, does in the economic environment. The enhancement of competition has as a result that as now the market is open (more hospitals are available, as also new private ones are built) the public and the individual as an actor has the opportunity to find and select the best suitable hospital for him/her. Nevertheless, for health in general, this means that hospitals have to take into account greater cost pressures from the patients (which are now transformed into customers) and from the government as insurance schemes cover a majority of patients and reimbursement rates have a huge effect on any hospital's overall financial performance. Additionally, these customers force for a treatment of better quality and as assistant in this demand comes also the government with its regulations that sets some minimum quality levels. Moreover, as the "market" is open, new competitors can emerge which can pressure the current established ones. Based on this, and as a reaction to this, also smaller healthcare providers in order to protect themselves make alliances which results to a centralisation of healthcare so that fewer, larger competitors in each market exist and the formation of multi-hospital networks is promoted (Adler and Riley, 2003).

In order to cope to the change in the environment, hospitals and doctors have to face also new accountability pressures aside from the existing ones. Until the beginning of the nineteen eighties, hospitals were accountable for the individual patient's health and for the maintenance of minimum acceptable quality levels. However, now that an increasingly economic focus is highlighted and for the sake of being effective and efficient hospitals and doctors become accountable: for the health of whole patient populations⁸, for cost in addition to the quality outcomes and finally not only for improving but on top of it also on trying to maintain the continually improved levels of performance.

As already seen, due to the changes in the environment and as a result of the socio-political changes in the beginning of the nineteen seventies the answer to the accountability question (to whom hospitals and doctors are accountable) is also changing. According to Adler and Riley (2003) in the past doctors were accountable primarily to their professional colleagues and to their personal sense of professionalism and hospitals were accountable to regulators for quality assurance. Nowadays however, after the changes in the relative power

⁸ which however has the problems mentioned in the introduction of this section, of focussing on populations however leaving apart patients

of the actors inside the health network, doctors are accountable to a broader set of stakeholders, which are among others hospital, regulators, employers, insurance companies, patients, and courts. In addition, hospitals are now more accountable for doctors' performance as they are also measured from the patients through mainly economic and qualitative criteria⁹.

Finalising, it could be stated that this economic rationalisation approach, based on the one side and promoted by the governmental decisions and on the other side being reinforced from within, once initiated has influenced the development of health in the last years. A concrete example for this is that of preventive medicine which is on the daily agenda. Quoting Haunschild (2003) "In accordance with general societal tendencies in the direction of individualisation and enhanced reflexivity (Beck 1986; Beck, Giddens, and Lash 1994; Petersen 1997), in our (mundane) everyday-life the reflection about dietary habits, bodily exercises and preventive medicine are on the daily agenda. All this requires judgements on what is desirable and what not; but what counts as the good life is in modern society highly influenced by the medical profession, i.e. medicine constitutes an influential political practice (cf. Turner 1996, pp. 200-1)".

2.6 Synthesis

In this chapter, the changes in the concept of health and on its theoretical foundations from the beginning of the sixties until now have been highlighted. This is mainly done in order to illustrate that the concept of health changes and it does not remain stable. In the centre of attention is the influence of the patient in this development. As the chapter has illustrated, the concept of health has changed as a result of changes and tensions between the actors about their relative power in the network. The most important actors that were identified explicitly or implicitly were the state, the medical authority be it physician or doctor and finally the patient.

If we examine in detail the different actors, we have seen in the health network, through its development, we could articulate some important remarks. The state has been the actor that has centrally controlled the network. However, it has never shown that it has the explicit power over the network and over the direction, it could follow. The medical authority, be it physician or doctor, has had in the beginning the power of the expert and thus controlled

⁹ Here it would be wise to state that quality can have also positive economic implications for the hospital. Normally a better quality of services compared to the competitors leads to an increase in the long run of the profitability of companies due to the increase in demand for the service.

the action of the patients as they had relatively less power. Nonetheless, through the development of the network, we can see that this relative power diminishes and we can see that, at the end, both medical authorities and patients are more or less on equal footing. Nevertheless, the tendency is that the medical authority loses its power, which moves in favour of the patients. Finally, the patients start with the less power, however, through the development gain significant influence.

Thus, summarizing, it could be stated that the change in the concept of health has been rather twofold: on the one side towards a market based system or better said treating health as a commodity that can be bought and on the other side from a centralised towards a more individualised based system. Actually, it could be said that there are currently two main trends that can be observed. The first is a more or less liberal trend that promotes the market system as a force that can regulate the general framework¹⁰ and the second is an increasing technological trend, which conveys with it a change in the importance of the individual. Through this trend, the individual now gains more power in comparison to the past. However, he or she has also the responsibility to use his power/knowledge in order to be able to participate in a healthcare system that changes through the increasingly use of technology.

¹⁰ In the same time the state moves into the background and keeps an observing function trying to ensure that there remains a certain balance and intervenes when this is not the case.

3 INTRODUCING E-HEALTH

Preface

In this chapter of the thesis, the concept of e-health will be introduced. Thus, the first section of the chapter will provide an overview of the concept of e-health and how it has developed. In its turn, the second section will give a synopsis of the European Union's approach of e-health. The third section will present the link between technology, health and economics that has been used in the actual development of e-health. Progressing, the fourth section is about the question of Determinism, while the fifth section highlights the ethical question of treating patients as customers. The sixth section of this chapter, discusses e-health and its development as a system/network with different actors and finally the seventh section provides a synthesis of the chapter.

Through the presentation of the development, we will observe that the introduction of e-health follows a rather similar logic in its development, or better said, starts there where the development of health presented in the last chapter ended. This means that it starts from a rather market based approach of treating health as a commodity. Nonetheless, this does not mean that its development persists also in the same tone. However before this part is analysed it is important to see what e-health brings and how it has developed.

3.1 An overview of the concept of e-health

As already stated, healthcare is a major issue for a country's welfare status in all levels, either economically and socially, or demographically. We live in an age that the healthcare sector demands on reducing costs and simultaneously on improving his quality and access to all (OECD, Docteur and Oxley, 2003). In the same time, the knowledge flow in the contemporary society, notifies the need for the use of new technologies both for the support of the traditional medicine through local, national and global sharing in practice methods

This appearance of information technology into society and consequently into healthcare with the objective to provide a solution to the increasingly rising demand for health and social services has led to the fact that the term e-health is increasingly used.

Nevertheless, only few people have come up with a clear definition of this comparatively new term. Hardly used before 1999, the term seems to serve as a general catchword used to characterize not only "Internet medicine", but also virtually everything related to computers and medicine. As it is the case with most e-words, (e-commerce, e-

business, e-mail) the term was first used by industry leaders and marketing people rather than academics as an attempt to communicate the promises, philosophy, and enthusiasm around bringing electronic commerce to the health arena, and to give an account of the new possibilities the Internet is opening up to the area of health care (Eysenbach, 2001). According to Eysenbach and a report of Deloitte and Touche, Intel referred to e-health as “a concerted effort undertaken by leaders in health care and hi-tech industries to fully harness the benefits available through convergence of the Internet and health care”. Hence, the philosophy behind the term e-health has been to use the internet and the information technology in order to respond to new features offered to health systems like the capability of consumers to interact with their systems online, the improved possibilities for institution-to-institution transmissions of data and finally the new possibilities for peer-to-peer communication of consumers. Therefore, from a managerial point of view, it is basically the attempt to capture the whole market as these challenges can be translated as business to consumer, business-to-business and finally consumer to consumer respectively. In an approach to provide an academic definition, Eysenbach defines e-health as “an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.”

3.2 A synopsis of EU’s approach towards e-health

Although the term e-health is relative new, this does not mean that the whole approach of using information technologies in the health sector is new. It is actually very old, but because the focus of the paper is in e-health in Europe, at this instant, it is time to see what the actions of the European Union have been during the last years. Of course, this synopsis is less than extensive, as the next chapter will deal more extensively with the policies of the EU about e-health.

In general, European Community research programmes have been supporting e-health over the last seventeen years. The financing allocated since the early ninety nineties, has reached € 500 million, with a total budget about twice that amount. Many of these research results have now been tested and put into practice, which resulted to the fact that Europe is in

a leading position in the use of electronic health records in primary care and deployment of health smartcards. These developments have contributed to the emergence of a new “e-health industry” that has the potential to be the third largest industry in the health sector with a turnover of € 11 billion. By 2010, it could account for 5% of the total health budget. This last decade and a half of regional, national, and international research and development in funding for e-health in Europe have resulted in a wide number of applications that have been implemented in several Member States. There are many good examples of e-health initiatives at a national and regional level within the European Union and with a variety in their focus. Some support the use of smartcards; others are large-scale health information networks supporting services. (COM (2004) 356 final)

More specifically, one interesting point to start the analysis of the development of e-health is the Bangemann report and the healthcare networks it proposes as application number seven in Chapter 4 “The building blocks of the information society”. In this section of Bangemann report it is explicitly stated that in order to implement less costly and more effective healthcare systems for Europe's citizens, a direct communication “network of networks” based on common standards linking general practitioners, hospitals and social centres on a European scale should be created. This should be done by “the private sector, insurance companies, medical associations and Member State healthcare systems, with the European Union promoting standards and portable applications. Once telecom operators make available the required networks at reduced rates, the private sector will create competitively priced services at a European level, boosting the productivity and cost-effectiveness of the whole healthcare sector”. The report continues stating that through the approach proposed “Citizens as patients will benefit from a substantial improvement in healthcare (improvement in diagnosis through on-line access to European specialists, on-line reservation of analysis and hospital services by practitioners extended on European scale, transplant matching, etc.). Tax payers and public administrations will benefit from tighter cost control and cost savings in healthcare spending and a speeding up of reimbursement procedures”. (Bangemann report, Chapter 4 “The building blocks of the information society” application number seven)

Into a more recently approach, the European Commission in the first high -level conference on e-health in 2003 defines e-health as “the application of information and communications technologies across the whole range functions that affect healthcare, from diagnosis to follow-up”. Furthermore, when it is combined with organisational changes and the development of new skills, e-health can help to deliver better healthcare for less money within citizen-centred health delivery systems. If we start from these definitions and

extrapolate them, it could be stated that “e-health is today’s tool for substantial productivity gains, while providing tomorrow’s instrument for restructured, **citizen-centred health systems** and, at the same time, respecting the diversity of Europe’s multi-cultural, multi-lingual health care traditions”. (COM (2004) 356 final)

However, the story does not end here, the Member States have shown that they are keen to take an e-health agenda forward, drawing on best practices and experience from across the Union. This could lead to new “European e-health Area” based on the different and diverse European policies and initiatives which however would be integrated in a Community level.

Furthermore, e-health plays a clear role in the European Union’s e-Europe strategy, and is a key to achieving stronger growth and creating highly qualified jobs in a dynamic, knowledge-based economy. This is a vision set out by the Lisbon European Council in March 2000. However, so that the vision can flourish action will be required within several important policy areas that range from research and the rollout of broadband networks in telecommunications, to action in public health, and work in Member States that promotes mobility and assesses the implications of European ageing on healthcare systems. Here, it must be also explicitly stated that Community action in the field of public health must fully respect the competence of the Member States in the field of health care. Nonetheless, actions and developments like e-health systems and services, which can have an impact on health systems, are not totally part of the national competences, but lie also in the community level. But even so, there is considerable demand from Member States for further action to promote best practices and share experience. For example, the Employment and Social Dimension of the Information Society collects best practices on the employment and social inclusion aspects of e-health and healthcare in the knowledge society. (COM (2004) 356 final)

The next section of the paper will provide the overview of the development of e-health and its link with technology and economics.

3.3 Link of technology health and economics

In this section of the paper, the link of the actual development between technology, the economy, and e-health is provided. According to Mitchell (1999), it is important to clearly distinguish between telemedicine, telehealth, health informatics, the information economy, e-commerce and e-health. This is vital in the sense that without proper definition of the concepts and as they are interlinked, some misunderstanding can arise. Furthermore, it is

important to make this division in order to be able to explain the development of e-health. Additionally it is essential, since term e-health has developed primarily based on the logic of economic development and of using health as another area, which can be sold as a product. Therefore, it is also an area that can be seen under the prism of the information economy. In order to have an overview of the concepts that have arisen, the following table summarises the common definitions of these terms.

Table 3.1: Brief definitions of key terms

| Term | Sample Definitions |
|---------------------|--|
| Telemedicine | <p>a system of health care delivery in which physicians examine distant patients through the use of telecommunications technology' (Preston, 1993)</p> <p>“The delivery of health care services between geographically separated individuals, using telecommunication systems e.g. video conferencing”. (Coeira, 2003).</p> |
| telehealth | health care at a distance (Health On Line, 1997) |
| health informatics | “The knowledge, skills and tools which enable information to be collected, managed, used and shared to support the delivery of healthcare and to promote health”. Making Information Count: A Human Resources Strategy for Health Department of Health October 2002 |
| Information economy | ‘the new world of social and commercial interaction, brought about by advances in information technology’ (Towards an Australian Strategy for the Information Economy, 1998) |
| e-commerce | ‘every type of business transaction in which the participants (i.e. suppliers, end users etc.) prepare or transact business or conduct their trade in goods or services electronically’ (Australia’s e-commerce Report Card, 1999) |
| e-health | ‘a new term needed to describe the combined use of electronic communication and information technology in the health sector ...the use in the health sector of digital data - transmitted, stored and retrieved electronically - for clinical, educational and administrative purposes, both at the local site and at a distance’ (From Tele-health to E-health, the Unstoppable Rise of E-health, 1999) |

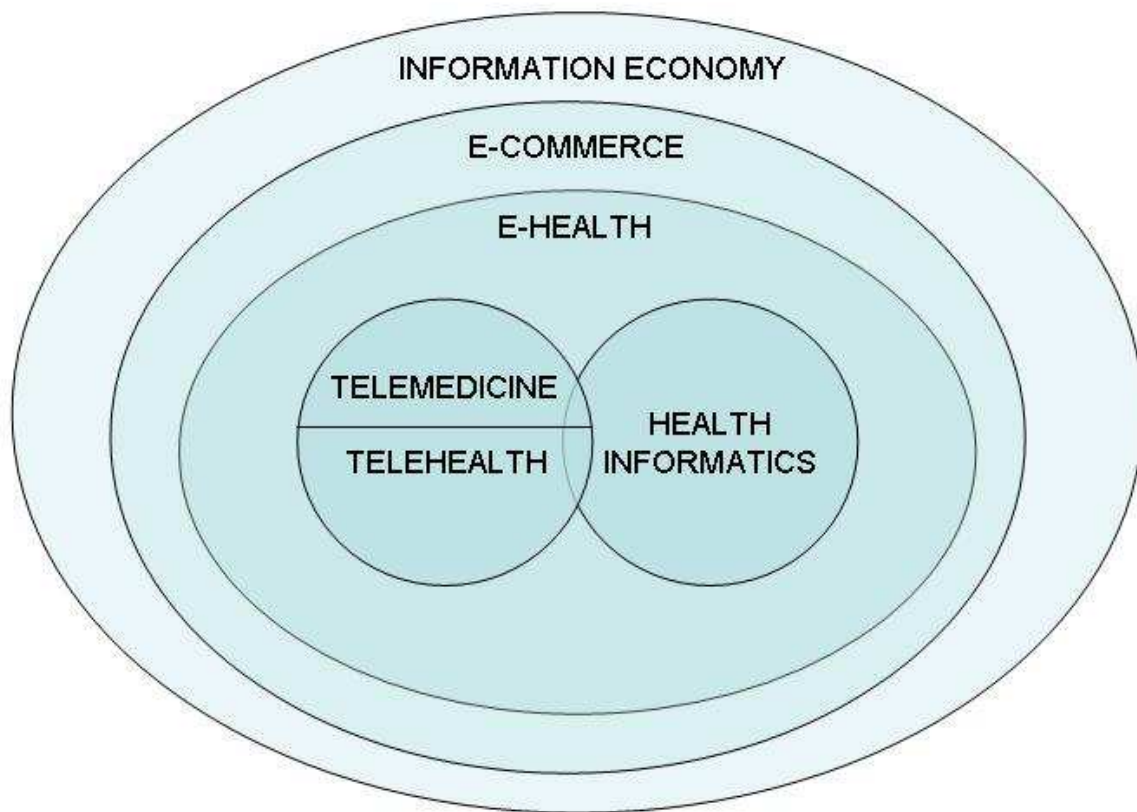


Figure 3.1: Relationship between key concepts (adopted from “The cost effectiveness of telemedicine enhanced by embracing e-health”, Mitchell J., 1999)

The above figure, which is in fact based on and depicts the beginning of the use of the term e-health, shows the relationship of the information economy and e-commerce to e-health, telemedicine and telehealth. The figure shows that e-health comprises both telemedicine telehealth and health informatics. Thus, this means that it is both the delivery of health care services between geographically separated individuals, using telecommunication systems e.g. video conferencing but also the knowledge, skills and tools that enable information to be collected, managed, used and shared to support the delivery of healthcare and to promote health. Actually, in the report by Mitchell (1999), e-health is taken to be the health industry’s component of e-commerce: ‘E-health is a new term needed to describe the increasing use of electronic communication and information technology in the health sector’. Hence, e-health is the overall, umbrella field that encompasses telemedicine and telehealth.

From the above figure we can indeed state that the development of e-health follows the logic of treating health as a commodity and actually bases on it, however, using the advantages the introduction of technology makes possible. Thus, we can state that e-health is

a product of this development as we introduce the technology factor without however changing the real philosophy of the development at least in its initial development.

Nevertheless, this leads to a critical point, which is the discussion of two major discourses in the development of e-health. The first of them is Information technology (IT) as progress and the second one is e-health as commerce.

3.4 Question of Determinism

Information technology (IT) as progress, resides mainly in the ubiquity and plausibility of the discourse of technological determinism. This discourse, epigrammatically states that the specific capacities of the technology can, do, and should drive reform and changes in social and institutional practices¹¹. Nevertheless this first discourse competes for status and influence with the power of medical practitioners (Horsfield & Peterson, 2000).

As we have seen in the previous chapter, the relative power of physicians and doctors in the health network has gradually diminished. Now, with the introduction of IT, this power is once again put into contestation¹². Consequently, we see that medical and clinical practitioners advocate the integration of IT into professional health environments. This introduction however displays clearly the sociotechnical discourse and is made under the premise that this introduction reflects specific needs arising from practice and experience (Horsfield & Peterson, 2000).

This means that for the medical practitioners it is not de facto that because information technology will be used the results will be better and thus there will be progress. This is a rather normal reaction as we are anxious about the introduction of technology and generally about everything new. Conversely, doctors and practitioners advocate the use of technology; nevertheless, only in such an extent that it reinforces their position in the health network. An element of demonstration of this approach can be seen also in the historical development of health. There, physicians and doctors promoted the development of diagnostic technologies as they were “objective” bodily measurements (e.g. x-rays, pathology and genetic tests) and it enhanced the power differential they had towards the patients (see also p. 13 notes 5 and 6).

¹¹ Nonetheless this belief is in fact a result of social determinism, in the sense that it bases on the belief we have about the world. What is meant is that the belief we have (that technology can help), is a product of our general frame of thought. In the same time however, this belief reinforces the theory we have that technology will drive reform and changes.

¹² Through the introduction of technology the expertise of the doctor is enhanced comparing to the specific expertise of the patient. This is mainly a result of the fact that the patient does not know the technology in contrast to the doctor who is able to use the technology (as the expert) to argue in favour of his diagnosis.

Furthermore, based on the work of Orlikowski “The Duality of Technology: Rethinking the Concept of Technology in Organizations”, IT is both shaped through the actions of human agents and the technology will also influence the actions and behaviour of users. Additionally, Hutchby (2001) like Orlikowski argues that technologies are both shaped by, and shaping the practices humans use. He furthermore argues that that the degree to which technologies can be interpreted through human agency is dependent upon the ‘affordances’, associated with a specific technological artefact. As he [2001; p 447] notes: “The affordances of aeroplane and bridge render available different ranges of uses, and subject those possible uses to different ranges of effects and constraints”. In this context, any specific information technology can be viewed as having a range of ‘affordances’, associated with its core functionality, which will limit the range of ways in which it can ultimately be interpreted or used.

The second major discourse, on which this figure is based, is e-health as commerce. As already stated, Mitchell (1999) maintains that e-health is a subset of e-commerce. However, this does not mean that this is actually, what happens or even better, what should happen. This figure presupposes that there is always an economic rationality behind each action. Under this perspective in the concept of e-health, patients are not merely patients but are fundamentally customers’. This of course once again raises the question of ethics and if treating patients as customers is ethical¹³.

3.5 The ethical question of treating patients as customers

Although we discuss the ethics of treating patients as mere customers, this does not mean that if you do not have the necessary money you will be left to die. This is not the point. The issue is if we find such an approach fruitful and acceptable. In sake of clarity at this instance it must be explicitly stated that health is considered a fundamental human right that is embodied in a number of international declarations, covenants and plans of action, that obligate states to ensure that all people enjoy the same access to goods and services essential to enjoyment of this right.

In order to provide an example of such a key text, we could look at Article 12 of the International Covenant on Economic, Social and Cultural Rights, to which 145 countries are

¹³ Ethics constitute a major part of the general discussion about healthcare and about the development of e-health. Nevertheless as any try to specifically focus on questions of ethics in this thesis would not be plausible due to the extend of the topic, ethics will unfortunately not be part of the discussion of this thesis

‘state parties.’ The Article proclaims “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. This Article, and its definitive 2000 ‘General Comment 14,’ specifically obligates the states which are its parties to ensure provision of a number of health care and public health services, as well as equitable and affordable access to key underlying health determinants such as “safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and health related education and information, including on sexual and reproductive health” (General Comment 14, 11).

3.6 e-health and its development as a system / network

e-health may have started with this economic rationality; however, it is currently developing in a network/systemic approach in which many actors have influence. One of those actors is industry. Even though the industry has dominated the network in the first phase of its formation and its early development with the form of e-health, this does not mean that, at this point of time, it has more influence than the others actors.

One of the other actors is the state that regulates through its policies the system/network. Here, it must be however said that in the last years the state has moderated its power and nowadays, only draws the general framework on which the network can develop. This, of course, leads us again to the observed trend of the movement from a centralised by the state approach into a more individualised, personalised based approach. The two other actors in the system of healthcare are the medical professionals, which have diminished in power and, of course, the most important actor for this thesis the patient.

Throughout this thesis we have seen that the patient although slowly, nevertheless steadily, has gained in power. Even though in the beginning the patient, had absolutely no power, as the power lay with the state and in the hands of the professionals, after the changes and the wider cultural and political shifts we see that the role is strengthened. Nonetheless, the questions arising are: what is the new relation? In addition, what is the place of the patient in the new system?

Some perceive that albeit a new very influential actor (the industry) appears into the healthcare system, and tries to take power over it; the position of the patient although in the beginning, suffers to become merely a consumer, at the remains powerful. What is even more,

it is hypothesised, that for some patients,¹⁴ the development of e-health facilitates as an anticipation of a new social arrangement around caring. However others, do not agree with the afore mentioned argumentation. They believe that patients are an important actor; nonetheless, they are by far not so powerful as medical professionals, or the industry.

Evidently, the importance and the role of patients in the development is very important and will be demonstrated in more detail in terms of policy papers. Yet, in fact, we could state that in the current situation there is comparatively a balance of power between the actors, as every actor is deemed equally important.

3.7 Synthesis

Concluding, this chapter has provided an overview of the concept of e-health and of its development. It has given, on a first level, a synopsis of the Europeans Unions approach of e-health as a theoretical background. The second level of analysis was the link between technology, health and economics that has been used in the actual development of e-health. Finally, we have discussed the development of e-health as a system/network with different actors, which gives a partial view of the approach that will follow.

Even so, what we can observe through the introduction of e-health is that it represents a new way of balancing power in the healthcare system between the different actors. If we compare this approach of e-health to the development of the healthcare network, we could ask ourselves if the balance of power has shifted towards the favour of the patients. Additionally, we could ask if this is caused by the change in the governmental approach now favouring decentralisation also in topics that were in the past deemed as necessary to be centralised.

Consequently, what we can conclude is that e-health is a new form of balancing power. In this new healthcare system that e-health brings with it, if we take the fact of the utilisation of technology as granted¹⁵, four major actors exist, industry, patients, doctors (medical professionals) and state. However, the state has as its' primarily role only an observing function and is organizing when it deems it necessary by setting the framework. Thus, it could be stated that the state moves into the background, which results, to a decentralisation of the system, while in the same time also a turn towards individualisation

¹⁴ Especially the ones neglected by the traditional healthcare system, due to the fact of not being "visible" to the system due to the rarity of their cases e.g. so-called 'orphan diseases'.

¹⁵ Although we take technology as granted it must be here stated that the reality that we take technology as granted is in fact a result of social determinism. This is in the sense, that the approach we take represents the hypothesis we have about the world.

can be observed. This is mainly a result of the fact that the three other actors, patients, industry and medical professionals, have to find a new equilibrium of power. This in turn, results in the fact that patients, through the use of technology and under the presupposition that they will be able to actively shape and thus not only be themselves shaped through technology, can influence the e-health network extensively¹⁶.

¹⁶ This is based on the opportunities and the possibilities information technology offers to citizens to acquire knowledge and find useful information. Additionally the e-health network is dynamic as it is also content dependent. Thus if the focus is in preventive medicine then the individual has more power as in cases where the focus is on evidence-based medicine, or new generations of computerised clinical systems where on the contrary the power lies in health professionals.

4 THE EU PAPERS ABOUT HEALTH

Preface

This chapter of the thesis discusses the development of the policies and the actions of the European Union in the development of e-health. Mainly the focus will be on policy paper analysis and on how e-health is presented from the EU through different policy papers. Introductorily, it could be stated that the policy papers of the European Union about the topic can basically be divided in two distinct levels/layers. The first layer is composed by strategic papers about the European Union in general, which however gave a push towards the development of e-health. An example of such a strategic paper, which will be examined principally as a starting point, is the “Bangemann report” as well as the e-Europe initiatives.

The second level of policy papers, are the different action plans like COM (2004) 356 final “E-Health - making healthcare better for European citizens: An action plan for a European e-Health Area”. Once again, the focus of attention, while discussing the policy papers, will be on the different actors emphasising more the positioning of patients as an actor in the healthcare network. In order to illustrate how the analysis of this policy papers will be made, the next section discusses the method used.

4.1 Method

Why is policy paper analysis important? There are mainly two important reasons to analyse such papers. First of all, policy papers are among the most important primary sources on which to rely when studying a certain policy field. Policy papers can be used as important clues that help us understand what “really” happens in a certain policy field. Additionally, there is second more theoretical reason why policy papers matter and why policy analysts should take them seriously. Policy documents are far from being merely neutral media that transmit information. Rather, they are of large influence on forming and making the political realities they describe. Thus, the analyst has to be informed about the metaphors, story lines and visual renditions that people use in policy related communication.

There are mainly two major strands of analysis when we speak about analyzing political discourses. The first is “discourse analysis” which is associated with Foucault and his innovative approach towards the analysis of Western intellectual history as presented in his books “The Archaeology of Knowledge” (1972), “Discipline and Punish” (1977) and “L’ordre du discours” (1971). Nowadays, discourse analysis includes macro-sociological studies

of political language and ideas, as well as, micro-sociological approaches to the analysis of everyday conversation. The second major strand is ethnographical research. Ethnography, can generally be characterised as the micro-sociological analysis of social practices from “the actors point of view” (Lachmund and Versluis, 2003).

In the context of this thesis, no single approach is preferred more than the other is. Thus, the analysis will use ideas from both discourse analysis and ethnography in a rather selective and goal oriented way. Nonetheless, in order to have a standardised method of analysis that is easy for the reader to compare the different papers and additionally, in order to be able to illustrate the shifts in thought, it has been decided to develop a table, for each of the papers discussed. This table illustrates the major actors, the focus of the paper and has as its objective ultimately to be able to show the changes in the approach and in the development. In the course of this approach it is expected that, on the one side, consistency in the analysis is guaranteed and on the other side, that the development is also visually highlighted. The following figure presents the four major actors (Patients, Industry, Doctors and medical authorities, and finally Government) which are identified in the papers as relevant actors and influence in one way or the other the development of e-health.

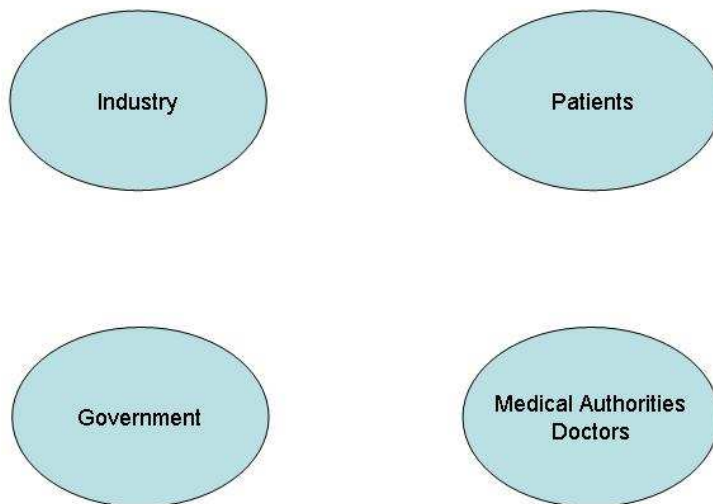


Figure 4.1: The major actors presented in the policy papers

4.2 The EU and the development of e-health.

Although the term e-health is relatively new, this does not mean that the whole approach of using information technologies in the health sector is new. Even though health is currently, a Member State responsibility¹⁷ (Appendix 1) and all Member States have their own health budgets and consequently e-health budgets, the European Community research programmes have in general supported e-health for the last seventeen years. The financing allocated, since the early 1990s, has reached € 500 million, with a total budget about € 1 billion. The last seventeen years of regional, national, and international research and development in funding for e-health in Europe have resulted in a wide number of applications that have been implemented in several Member States (COM (2004) 356 final). There are many good examples of e-health initiatives at a national and regional level within the European Union and with a variety in their focus. Some support the use of smartcards, others are large-scale health information networks supporting services. This has led to the fact that the European Union is now in a leading position in the use of electronic health records in primary care and deployment of health smartcards. (COM (2004) 356 final). Nevertheless, in order to observe the development in total it is wise to begin the analysis based on a starting point, which in this case, will be the Bangemann report.

4.3 Strategic papers

This section discusses the strategic papers developed in the course of the development of e-health. The approach favoured is to examine the papers in a chronological manner beginning from the Bangemann report and continuing with the *e*Europe action plans 2002 and 2005. This chronological approach is preferred in order to be able to better illustrate the interconnection between the changes taking place. Thus, the paper tries to demonstrate that the introduction of technology in e-health and the development in its continuous phases is step-wise linked.

¹⁷ This is subject to be changed as if the Constitutional Treaty for Europe is ratified then the competencies about public health will change, as appendixes 1 and 2 illustrate. If the constitution is ratified then the union will be able to facilitate co-operation between the Member States, respecting the Member States' responsibilities for organising and managing their health systems. Through the new treaty for the first time the *well being* of people living in Europe becomes an aim of the EU (article I-3: the Union's objectives). Access to preventive health care and treatment is a fundamental right (article II-95). The European Commission has a stronger mandate to fight health threats, including tobacco and alcohol.

4.3.1 The Bangemann report

One very interesting point to start the analysis of the development of e-health is the Bangemann report and the healthcare networks it proposes as application number seven in Chapter 4 “The building blocks of the information society”.

This report can be characterised as being very liberal as it treats e-health as an application, which can be helped by the movement in the information age. Thus, it could be stated that, in this report, e-health is actually seen as an application, which follows a primarily economic and industrial logic. Of course, this is not very striking if we acknowledge the fact that the report is promoting the building of new infrastructure. Under this perspective, it is rather normal to propose some possible applications in order to illustrate on the one side the necessity of the investment and on the other side also potential markets, which could bring profit for companies and serve the general public. Secondly, it is wise to witness the background of the initial promoter of this report Mr. Martin Bangemann¹⁸ and also the wider political situation (mainly liberal and conservative governments in the European Union, and large investments in technology worldwide) as also the fact that this report is primarily linked to what is nowadays referred to as DG Enterprise.

The Bangemann report “urges the European Union to put its faith in market mechanisms as the motive power to carry us into the Information Age. This means that actions must be taken at the European level and by Member States to strike down entrenched positions which put Europe at a competitive disadvantage”:

- it means fostering an entrepreneurial mentality to enable the emergence of new dynamic sectors of the economy
- it means developing a common regulatory approach to bring forth a competitive, Europe-wide, market for information services
- it does NOT mean more public money, financial assistance, subsidies, dirigisme, or protectionism.

In chapter 4 of the Bangemann report is explicitly stated that in order to implement less costly and more effective healthcare systems for Europe's citizens, a direct

¹⁸ Mr. Bangemann was during his remarkable political career Secretary-General and subsequently Chairman of the FDP (Free Democratic Party) in Germany and chairperson of the Liberal and Democratic Group in the European Parliament. Additionally he was Federal Minister of Economic Affairs, Vice-President of the European Commission, responsible for the internal market, industrial affairs and relations with the European Parliament and finally member of the European Commission, responsible for industrial affairs and information and telecommunications technologies.

communication “network of networks”, based on common standards linking general practitioners, hospitals and social centres on a European scale, should be created. This should be done by “the private sector, insurance companies, medical associations and Member State healthcare systems, with the European Union promoting standards and portable applications. Once telecom operators make available the required networks at reduced rates, the private sector will create competitively priced services at a European level, boosting the productivity and cost-effectiveness of the whole healthcare sector”. Through this advance, “Citizens as patients will benefit from a substantial improvement in healthcare (improvement in diagnosis through on-line access to European specialists, on-line reservation of analysis and hospital services by practitioners extended on European scale, transplant matching, etc.). Tax payers and public administrations will benefit from tighter cost control and cost savings in healthcare spending and a speeding up of reimbursement procedures”. (Bangemann report, Chapter Four “The building blocks of the information society”, application seven).

From the above, it is clear that the main focus of this paper is on building the technical infrastructure, which can be used in different applications like for instance in the healthcare system. However, as soon as we focus on the healthcare applications, what can be observed is that the patient as an actor is not actively participating in the development of the networks, or in the applications developed, but remains a user of them. Implicitly, it could be stated that the patient/citizen will be the customer/consumer of the services produced, which evidently, once more advocates the belief that in the Bangemann report about healthcare networks, the focus is on industry and on building the infrastructure. Additionally, as the state does not use its influence either as an actor or as an implementation factor, but urges the private sector to do so we could speak about a decentralized approach in which the market is the main regulatory force. Certainly, this is done under the observation of the state/government, which however does not intervene actively.

In the table below, we can see that, in the Bangemann report, the main influential actors are industry and the medical professionals as on the one hand, the industry is responsible for the infrastructure and the medical professionals are the experts. In addition, we are able to see that patients are merely acknowledged as customers by the report and that government plays not a very active role as market mechanisms will be the motivating power to carry us into the Information Age, and the state will have observation of the procedure.

Table 4.1: The Bangemann report

| | |
|-------------|---|
| Actor(s) | Industry (Most important actor as responsible for the infrastructure) Medical authorities (Experts in their field, professional knowledge) Patient (In this report they are merely customers) Government (Observing the general framework) |
| Major issue | Building Infrastructure, Technical |
| Health | Treated as a commodity |
| E-health | Use technology to offer direct communication, and on-line access to European specialists, and hospital services |

As already stated the Bangemann report can be seen as an initial point to start the analysis of the development of e-health in the European Union, still it is, by far, not the last. The next section of this chapter will discuss another strategic paper of the European Union that deals also with the general developments in the field of e-health.

4.3.2 The eEurope initiative and eEurope Action Plan 2002

In this section, the communication paper “An Information Society For All Communication on a Commission Initiative for the Special European Council of Lisbon, 23 and 24 March 2000” will be discussed. Although this paper is a communication of the European Union in order to demonstrate to the public the objectives set, the reader is able to observe some interesting changes in the language used. For instance, for the first time the word citizen appears and also society is mentioned. Nevertheless, before beginning the analysis it is wise to mention what the eEurope initiative is.

To begin with, on 8th December 1999 the European Commission launched an initiative entitled “eEurope: An Information Society for All”, which proposed ambitious targets to bring the benefits of the Information Society within reach of all Europeans. The initiative focused on ten priority areas, from education to transport and from healthcare to the disabled. Quoting “eEurope is a political initiative to ensure the European Union fully benefits for generations to come from the changes the Information Society is bringing”. “These changes are not just about technology. They affect everyone, everywhere. It will bring communities closer together, creating wealth, and sharing knowledge” (Communication on a Commission Initiative for the Special European Council of Lisbon, 23 and 24 March 2000 p.2). In fact, for the European Union “managing this transformation represents the central economic and social

challenge as its impact will be profound on European employment, growth and productivity for the next five years and for decades afterwards” (p.2). The initiative “aims at ensuring that the change towards the Information Society is cohesive, integrative and an opportunity and that it does not prove to be divisive, fragmenting and a threat” (p.2).

The key objectives of *e*Europe as presented in page 2 of the communication are the following:

- Bringing every citizen, home and school, every business and administration, into the digital age and online.
- Creating a digitally literate Europe, supported by an entrepreneurial culture ready to finance and develop new ideas.
- Ensuring the whole process is socially inclusive, builds consumer trust and strengthens social cohesion.

Now that the general framework of the *e*Europe initiative has been presented, it is time to focus on the section of the paper that discusses online healthcare. Initially, the section states that “the efficient provision of quality health services to all citizens in the future is one of the most difficult challenges facing all European governments” (p.14). Healthcare technology and treatment improves dramatically at the same time as the problem of ageing population appears which of course has financial implications. “Thus there is a double challenge: to improve the quality and accessibility of health care for all the citizens of the Union, whilst constraining overall costs”. As a solution to this problem comes “the deployment and widespread use of fully integrated, interoperable and modernised health systems. Digital technologies can improve the productivity and scope of health care” (p.14).

The initiative goes on focussing on financial data and the importance of healthcare as an industry “Health care is a major business. EU governments spend, on average, over 8% of GDP on health. Consequently, building a single market in health care products and services will have an important impact on the future competitiveness of Europe”. Furthermore, it goes on to state that “in this context, the Union has every incentive to co-operate in the protection and improvement of public health (Article 152 of the Treaty). This does not mean harmonising health care at European level. However, it does mean working together by conducting research, agreeing standards and product specifications and building pan-European medical libraries”. Finally, following this initiative in June 2000 the *e*Europe 2002

Action Plan was agreed by Heads of State and Government in Feira. This action plan¹⁹ sets out a roadmap to achieve eEurope's targets. In the plan, it is stated that “the Lisbon European Council indicated that real efforts must be made by public administrations at all levels to exploit new technologies to make information as accessible as possible”. Furthermore, some concrete actions of the European Union are agreed upon. These actions can be seen in the table below

Table 4.2: eEurope Action Plan - Health online (adopted from eEurope 2002 Action Plan)

| Action | Actor (s) |
|--|-----------------------------------|
| Ensure that primary and secondary healthcare providers have health telematics infrastructure in place including regional networks. | Member States |
| Best practice in electronic health services in Europe identified and disseminated, benchmarking criteria set. | Member States, EC, Private Sector |
| Establish a set of quality criteria for health related websites. | EC, Member States, Private Sector |
| Establish health technology and data assessment networks. | EC, Member States, Private Sector |

Commenting on the eEurope initiative it could be stated that, first of all, it is what we could define as technological deterministic as it presupposes that the specific capacities of the technology can, do, and should drive reform and changes in social and institutional practices. Secondly, the initiative makes use of the words citizens and society quite extensively. Nonetheless, when it comes into e-health, it focuses mainly on the potentials of the healthcare industry and not on the health of the citizens or on the way the citizens will be empowered by the use of technology. Moreover, based on the fact that in the paper words like competitiveness, costs, and healthcare products are used quite often, we could assume that the paper is influenced by an economic rationality and its logic. This means that actually, what is asked by the paper is to inform citizens about the possibilities that exist to use the new technologies however not by directly involving them in the shaping of the technology but more or less to use what is already developed.

If we now draw the table, we can observe that the main actors are industry and the government (in this case it is meant both Member States and European Commission). Medical

¹⁹ An action plan is a specific document used to guide the implementation method or process to achieve the results called for by one or more objectives. It may contain task assignments, milestones, and timelines.

professionals are included based on their professional knowledge and from the fact that they will be able to be more efficient and effective. Albeit patients or, better said in this case, citizens are rhetorically included, and are as well included in the sense that the government works for the good of its citizens, they still do not participate actively in the development.

Table 4.3: The eEurope initiative and eEurope Action Plan 2002

| | |
|--------------|---|
| Actor(s) | <ul style="list-style-type: none"> - Industry (Health care is a major business. Building a single market in health care products and services will have an important impact on the future competitiveness of Europe) - Medical authorities (Experts in their field, professional knowledge) - Patient/Citizen (Inform them about the benefits of information technology) - Government (Work together by conducting research, agreeing standards and product specifications and building pan-European medical libraries) |
| Major issues | <p>-eEurope is a political initiative to ensure the European Union and its citizens fully benefits for generations to come from the changes the Information Society is bringing.</p> <p>-eEurope Action Plans form an integral part of the European Union’s overall aim to achieve the Lisbon targets of stronger growth creating more jobs within a dynamic, knowledge-based economy as set out by the Lisbon European Council in March 2000</p> <p><u>Objectives.</u></p> <ul style="list-style-type: none"> - Bring every citizen, home and school, every business and administration, into the digital age and online. - Create a digitally literate Europe, supported by an entrepreneurial culture ready to finance and develop new ideas. - Ensure the whole process is socially inclusive, builds consumer trust and strengthens social cohesion |
| Health | <ul style="list-style-type: none"> - Treated as a commodity. - Double challenge: Improve the quality and accessibility of healthcare for all the citizens of the Union, whilst constraining overall costs |
| E-health | <ul style="list-style-type: none"> - Deployment and widespread use of fully integrated, interoperable and modernised health systems. Digital technologies can improve the productivity and scope of healthcare. |

The advance of the role of the citizens in comparison to prior papers can be partially explained by the fact that the 5th Framework Programme (1999-2002), which will be discussed extensively in chapter five, was about societal demands and thus also the needs of society should be represented. Additionally, by 2000 the Directorate General that was in charge of the Information Society including e-health was the Information Society and

Enterprise which tried to combine both an entrepreneurial approach and to bring citizens closer to the notion of the information society.

4.3.3 The *e*Europe initiative and *e*Europe Action Plan 2005

The *e*Europe action plan 2002 was after two years replaced or better said followed by the *e*Europe 2005 action plan. The action plan 2005, followed that of 2002, as part of the Lisbon strategy to make the European Union the most competitive and dynamic knowledge-based economy with improved employment and social cohesion by 2010. It is actually based on the premises of the previous action plan that reshaped the regulatory environment for communications networks and services and for e-commerce and opened the door to new generations of mobile and multimedia services. The *e*Europe 2005 action plan, has as its objective, “to provide a favourable environment for private investment and for the creation of new jobs, to boost productivity, to modernise public services, and to give everyone the opportunity to participate in the global information society” (COM (2002) 263 final). Thus, it aims for greater citizen participation and also mobility. As the document states, “*e*Europe 2005 puts users at the centre. It will improve participation, open up opportunities for everyone and enhance skills. *e*Europe contains measures regarding e-inclusion in all action lines. One important tool to achieve this is to ensure multi-platform provision of services” (p.3). Ultimately, it must be stated that for the financial support for the implementation of the *e*Europe 2005 action Plan the Modinis programme is used²⁰.

Summarizing, it could be stated that the *e*Europe 2005 Action Plan is based on the *e*Europe 2002 action plan however emphasising more citizen participation. This becomes clearer if the proposed actions are observed. These actions include Electronic health cards, Health information networks and Online health services. Possibly, the most interesting actions for patients are the online health services and of course the Electronic health cards.

Concerning online health services, it was decided that “by end 2005, Commission and Member States will ensure that online health services are provided to citizens (e.g. information on healthy living and illness prevention, electronic health records, teleconsultation, e-reimbursement). Some of the health and related preventative services (e.g. air and water quality online information) could be expanded to a trans-European level through

²⁰ This sets four generic objectives: a)Monitoring and comparison of performance, b)Dissemination of good practices, c)Analysis and strategic discussion, and finally d)Improvement of network and information security

the eTEN²¹ programme. The Commission will monitor actions taken by Member States to make health information as accessible as possible to citizens as well as initiatives to implement quality criteria for web sites”. When it comes to Electronic health cards (EHR), its importance for citizens lies to the fact that the action increases patient mobility on the one side and on the other side combats bureaucracy. Until now, the case was the following: If a citizen of the EU wanted to visit another country then in order to receive health treatment he or she had to have some paper based forms with him, which s/he had to obtain prior to his/her departure from his national insurance and medical services. With the new European health insurance card, this changes, as the card replaces these forms.

Table 4.4: The eEurope initiative and eEurope action plan 2005

| | |
|--------------|---|
| Actor(s) | <ul style="list-style-type: none"> - Industry (Health care is a major business. Promote take-up of e-business with the aim of increasing the competitiveness of European enterprises and raising productivity and growth through investment in information and communication technologies) - Medical authorities (Experts in their field, professional knowledge. Digital technologies offer the potential to reduce administrative costs, to deliver health care services at a distance, to avoid unnecessary duplicate examinations) - Patient/Citizen (Puts users at the centre. Improve participation, open up opportunities for everyone and enhance skills) - Government (Policy measures to review and adapt legislation at national and European level, ensure that legislation does not unnecessarily hamper new services. Strengthen competition and interoperability. Improve access to a variety of networks. Facilitate the exchange of experience, of good practices and demonstration projects, but also of sharing the lessons from failures. Co-ordination of existing policies) |
| Major issues | - Provide a favourable environment for private investment and for the creation of new jobs, to boost productivity, to modernise public services, and to give everyone the opportunity to participate in the global information society. |
| Health | - Treated as a commodity. Improve the quality and accessibility of healthcare for all the citizens of the Union. Constrain overall costs |
| E-health | - Specific actions, which include Electronic health cards, Health information networks and online health services. As also information on healthy living and illness prevention, electronic health records, teleconsultation, e-reimbursement |

²¹ eTEN is the European Community Programme designed to help the deployment of telecommunication networks based services (e-services) with a trans-European dimension. It focuses strongly on public services, particularly in areas where Europe has a competitive advantage. Its objectives are at the very heart of the eEurope mission of “an information society for all”.

4.4 Action plans and conferences about e-health

Now that we are familiar with the general developments in the information society, it is time to look more concretely in the area of interest of this paper namely in e-health papers. This section of the chapter discusses the more specific action plans about e-health and also the high level/Ministerial conferences about the topic. This is an extra section of the chapter, as these documents are at the core of the focus of the topic and thus highlight more deeply the potential it has and the relevant actors. The section begins chronologically with the 1st high-level conference on e-health and continues with the action plan COM (2004) 356 final. Subsequently the 2nd and 3rd high-level conferences will be discussed.

4.4.1 1st High level conference

The Commission, in collaboration with the Greek Presidency, organised on the 22nd and 23rd May 2003 in Brussels, a high-level conference on e-health. The conference was aimed at ministers and senior representatives of stakeholder groups such as professional and user organisations, while developers along with current users of e-health applications participated in the exhibition. In addition, the event included a two-day exhibition of 30 e-health applications. In the frame of this conference, the first “eEurope Awards in eHealth” were attributed to the selected number of the conference exhibitors.

The objective of the conference was to provide Health Ministers and the health public sector in general with validated information on which key implementation decisions on e-health may be made. A second objective was to reinforce the implementation and deployment of e-health systems by European health service providers. The primary tool was the use of carefully selected real life demonstrations of currently working tools and applications. These were presented at the conference and at the exhibition, through real-time demonstrations. The conference, marked a turning point from the prioritisation of research issues in e-health to active implementation of the outcomes of that research, provided an important opportunity for Ministers and other key decision-makers to see the full potential of e-health solutions. The Ministers underlined their support for co-ordinated implementation of e-health solutions through a Ministerial Declaration on e-health.

In the Ministerial Declaration issued on 22nd May 2003, “ministers expressed their commitment to the development of national and regional e-health implementation plans as an integral part of eEurope 2005. Ministers declared their willingness to work together towards best practices in the use of Information and Communication Technologies (ICT) as tools for

enhancing health promotion and health protection, as well as quality, accessibility and efficiency in all aspects of healthcare delivery”. Additionally, they reaffirmed “that e-health applications can enhance efficiency and bring added value to health care by avoiding duplicate or unnecessary diagnostic or therapeutic interventions, by supporting the continuity of care, by improving communication between healthcare establishments and by widening access to health knowledge and evidence-based medicine”. Moreover, “the ministers shared the view that citizens' needs must be at the centre of attention in the development of high quality health related information services. Ministers noted the potential for citizen empowerment through widespread availability of high quality appropriate health information on the internet”. Finally, they agreed to implement and share best practices of e-health.

Analyzing the first High-level conference it could be stated that, for the first time, there is a more specific approach towards the topic of e-health focusing, not only on the information needs, but more on the health question. This of course is also a result of being a conference of the European Health ministers. Thus, it could be stated that since by this point the general technological framework has been established the more specific actions about the topic can be processed, and therefore also the introduction of stakeholders groups can be observed.

Table 4.5: 1st High-level conference

| | |
|--------------|--|
| Actor(s) | <ul style="list-style-type: none"> - Medical authorities (Professionals) - Patient/Citizen (Stakeholder groups, user organisations) - Government (Health Ministers) - Developers & current users of e-health applications participated in the exhibition |
| Major issues | - Provide health ministers and the public sector with validated information on which key decisions on e-health may be made. Reinforce the implementation and deployment of e-health systems by European health service providers. Citizens’ needs must be at the centre of attention in the development of high quality health related information services. Potential for citizen empowerment |
| Health | - Efficient national planning and evaluation of health policy, as well as cost effective delivery of health care, require speedy, accurate and comprehensive exchange of data. |
| e-health | - e-health can enhance efficiency and bring added value to health care by avoiding duplicate or unnecessary diagnostic or therapeutic interventions, by supporting the continuity of care, by improving communication between healthcare establishments and by widening access to health knowledge and evidence-based medicine. |

4.4.2 Action plan on e-Health - making healthcare better for European citizens

Into a more recent approach the European Commission with the communication²² dated 30th April 2004 from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions titled “e-health - making healthcare better for European citizens: An action plan for a European e-Health Area” states that “e-health is today’s tool for substantial productivity gains, while providing tomorrow’s instrument for restructured, **citizen-centred health systems** and, at the same time, respecting the diversity of Europe’s multi-cultural, multi-lingual health care traditions”.

This action plan focuses mainly on the actors and the influence e-health will have on them. The action plan identifies e-health as systems and services that benefit the health sector. Nevertheless, when it discusses the actors that can enjoy the benefits of e-health, it titles the first section as 2.2 “Empowering health consumers: patients and healthy citizens” and there, its focus is on citizen and patient aspects. “Both as patients and as healthy citizens, people can benefit from better personal health education and disease prevention. They need support in managing their own diseases, risks – including work-related diseases – and lifestyles. A growing number of people are looking proactively for information on their medical conditions. They want to be involved actively in decisions related to their own health, rather than simply accepting the considerable discrepancy (‘asymmetry’) in knowledge between themselves and health professionals. e-Health services provide timely information tailored to individuals in need. Specialised online resources are available for health education, safety and security at work, and lifestyle management. The Commission has been active in establishing quality criteria for Health related websites and accessibility of web sites”.

The action plan then continues with the identification of the other important actors providing respectively a section. Thus, section, 2.3 is about assisting health professionals, section 2.4 is about supporting health authorities and health managers and finally section 2.5 is titled as e-Health: the third largest industry in the European health sector. Subsequently in the third chapter, the state of play is discussed and in the fourth chapter, we can see the action plan (is a calendar form) towards the European e-health area²³. In this detailed action plan, most of the actions identified have a tone of a more patient oriented approach.

²² COM documents are proposed legislation and other official Commission communications to the Council and/or the other institutions, and their preparatory papers

²³ In Appendix 4 the concrete actions the action plan proposes and additionally the time and the responsibility can be found.

Table 4.6: Action plan e-Health - making healthcare better for European citizens

| | |
|--------------|---|
| Actor(s) | <p>- Medical authorities e-health tools and applications can provide fast and easy access to electronic health records at the point of need. They can support diagnosis by non-invasive imaging-based systems. They support surgeons in planning clinical interventions using digital patient specific data, provide access to specialised resources for education and training. Digital data transfer enables more effective networking among clinical institutions across Europe.</p> <p>- Patient/Citizen (Stakeholder groups, user organisations) Patients and citizens benefit from a better personal health education and disease prevention. They need support in managing their own diseases, risks and lifestyles. Personalised systems for monitoring and supporting patients are also currently available. These systems can help shorten or completely avoid patients in hospitals, while ensuring monitoring of their health status. Additionally, having access to comprehensive and secure electronic health records has been shown to improve quality of care and patient safety.</p> <p>- Industry e-health is emerging as the new “industry” alongside pharmaceuticals and the medical devices sector. By 2010, e-health spending may account for up to 5% of the total health budget of the 25 Member States from just 1% in 2000 (for 15 Member States). European businesses have every opportunity to become leading global players in this new industry</p> <p>- Government Extensive influence as it is mainly member state responsibility</p> |
| Major issues | <p>- Rising demand for health and social services, due to an ageing population and higher income and educational levels. Increasing expectations of citizens who want the best care available and at the same time to experience a reduction in inequalities in access to good health care. Increasing mobility of patients and health professionals within a better functioning internal market. Provide the best possible health care under limited budgetary conditions.</p> |
| E-health | <p>- e-health systems and services combined with organisational changes and the development of new skills are key enabling tools. They can deliver significant improvements in access to care, quality of care, and the efficiency and productivity of the health sector. The e-business aspects of e-health can become key drivers for change, and productivity gains, in such areas as infrastructure and skills development, internal business processes, procurement procedures and supply chain management, marketing and sales, and functions of the extended business</p> |

The above table shows that the action plan, both in its rhetoric about citizens and patients (which are in the case of prevention and information tautological as in prevention and information citizen and patient are connected if not the same), as also with its detailed actions provides a gradual shift towards more patient inclusion. This goes hand on hand with other

goals merely cutting down costs and reducing bureaucracy, however it is a positive signal towards the patients-citizens, which in due course appear, but also are, more empowered.

4.4.3 2nd High level conference

Anchored in the same tone with the action plan followed the 2nd High level conference that took place in Cork, Ireland, on 5th and 6th May 2004. The conference, focused on the three themes of the call for the eEurope e-health Awards 2004. These were e-health information tools and services for citizens, e-health administrative tools and services for citizens and finally e-health homecare and telemedicine tools and services for citizens. These e-health Awards 2004 will be more extensively discussed in chapter 6 that focuses on some of the best cases that can be seen in the development of e-health.

4.4.4 3rd High level conference

The last High-level, Ministerial e-health conference took place on the 23rd and 24th May in Tromsø, Norway. The focus of the conference was on the role of e-health in relation to facilitating mobility within and between countries, supporting more responsive health services and creating greater public awareness through better health information and improving access to and quality of care, patient safety, and productivity. Founded on the conference conclusions, European citizens are becoming more health literate and more involved in their personal healthcare. The use of the Internet as a key resource for health information and education has the potential to enable more patients to be treated, supported and monitored in the comfort and safety of their own homes, work places and leisure environments.

Additionally, it is acknowledged that medical errors and accidents cost thousands of lives as well as millions of euros every year. However, through the use of e-health tools such as electronic prescribing and real-time decision support coupled with integrated, interoperable electronic health records, the number of such accidents and errors can be reduced significantly. Furthermore, also health professionals can gain from efficient e-health tools that facilitate more flexible and collaborative work within and between health institutions as well as between traditional healthcare spheres, such as primary and secondary care and home care.

4.4.5 Future actions - i2010

The forthcoming closure of the eEurope 2005 Action Plan at the end of 2005, leads to the discussion of the actions that will follow. In general, the new i2010 - A European Information Society initiative will stimulate the take-up of information and communication technologies, to continue the eEurope agenda. The i2010 initiative promotes a clear, stable and competitive environment for electronic communications and digital services - an European information space; increased research and innovation in information and communication technologies; and an Information Society dedicated to inclusion and quality of life. Its objective is, to support European citizens through the creation of a safe, reliable, efficient and accessible e-health infrastructure, which not only meets the demands of national health strategies, but also develops a European-wide preparedness to address trans-border health challenges and crises. Finishing this section, it should be mentioned, that the upcoming 4th High-level conference in Malaga, Spain in the period 10-12 May 2006 will place emphasis on the importance of regionalism in healthcare.

4.5 Synthesis

Concluding, this chapter provides an overview of the different strategic and action papers behind the development of e-health in the European Union. In order to do so the papers were divided in two distinct levels/layers. The first layer was composed by strategic papers about the European Union, which gave a push towards the development of e-Health and the second level of policy papers were the different action plans and high-level conferences.

Summarising the findings, it could be stated that a trend that is visible as also hypothesized in the last chapter is the increasingly empowerment of the citizens/patients as also the continuing decentralization and individualization of the framework. Thus, it could be stated that we move towards what could be best described as personalized healthcare. Additionally, what is clear is the objective to include the patients/citizens in the development of e-health as stakeholders. Visually, the progress in the European policy can be best observed in the following tables that summarize the phases of the development for the different actors and the main issues to be found in the reports.

Nonetheless, the process is far than complete as currently patients have only an advisory role; they fulfil merely a consultation function. As we know the European Union

through its white paper on Governance²⁴ (COM (2001) 428 final) is aware of the problem, already mentioned in the introduction, of democratic control of so complicated systems and of the importance of more involvement and more openness of the system to the citizens. Nevertheless, although it is a very important first step, limiting the involvement of the citizens, only in an advisory role, is not the solution to the problem. Thus, movement towards further improving citizen participation, by active involvement, (also as a potential answer to the general question of democracy and legitimization taking place in the Union) should be made.

Table 4.7: The major issues and their development

| | Bangemann Report | eEurope 2002 | eEurope 2005 | 1stHigh level conference | Action plan e-health |
|---------------------|------------------------------------|---|---|--|--|
| Major issues | Building Infrastructure, Technical | Political initiative to ensure the European Union & its citizens fully benefits for generations to come from the changes the Information Society is bringing. Ensure the whole process is socially inclusive, builds consumer trust & strengthens social cohesion | Provide a favourable environment for private investment & for the creation of new jobs, to boost productivity, to modernise public services, & to give everyone the opportunity to participate in the global information society. | Provide health ministers & the public sector with validated information on which key decisions on e-health may be made. Reinforce the implementation & deployment of e-health systems by European health service providers. Citizens' needs must be at the centre of attention in the development of high quality health related information services. Potential for citizen empowerment | Rising demand for health & social services, due to an ageing population & higher income & educational levels. Increasing expectations of citizens who want the best care available and at the same time to experience a reduction in inequalities in access to good health care. Increasing mobility of patients & health professionals within a better functioning internal market. Provide the best possible health care under limited budgetary conditions. |

²⁴ Some of the goals are: 1) Establish a more systematic dialogue with representatives of regional and local governments through national and European associations at an early stage in shaping policy. 2) Bring greater flexibility into how Community legislation can be implemented in a way, which takes account of regional and local conditions. 3) Establish and publish minimum standards for consultation on EU policy.

Table 4.8: The major actors and their development

| Actor(s) | Bangemann Report | eEurope action plan 2002 | eEurope action plan 2005 | 1stHigh level conference | Action plan e-health |
|----------------------------|------------------------------------|--|--|--|---|
| Industry | Responsible for the infrastructure | Healthcare is a major business. Building a single market will have important impact on the competitiveness of Europe | Healthcare is a major business. Promote take-up of e-business with the aim of increasing the competitiveness productivity & growth | Developers participated to the exhibition | e-health is emerging as the new “industry” alongside pharmaceuticals & the medical devices sector. European businesses have every opportunity to become leading global players |
| Medical authorities | Experts, professional knowledge | Experts, professional knowledge | Experts professional knowledge. Digital technologies can reduce administrative costs | Professionals | E-health tools & applications can provide fast & easy access at the point of need. Support the diagnosis |
| Patient | Merely customers | Inform them about benefits of IT | Users at the centre. Improve participation, open up opportunities for everyone & enhance skills | Stakeholder groups, user organisations | Stakeholder groups, user organisations Patients & citizens benefit from a better personal health education & disease prevention. Personalised systems for monitoring & supporting patients |
| State | Observing the general framework | Work together by conducting research, agreeing standards & product specifications | Policy measures to review & adapt legislation at national & European level, ensure that legislation does not unnecessarily hamper new services. Strengthen competition & interoperability. Improve access, Facilitate the exchange of experience, & good practices | Health Ministers as also IT and Telecoms Ministers | Extensive influence as it is mainly member state responsibility |

5 IMPLEMENTATION OF E-HEALTH INITIATIVES

Preface

In this Chapter, the thesis examines the implementation of the e-health initiatives undertaken by the European Commission. Accordingly, the objective of this chapter is to investigate how the strategic papers, the action plans and the eEurope initiatives seen in the previous chapter have been put into operation.

In order to achieve the objective set, the chapter will discuss the two major Framework Programmes financed by the European Commission that deal among others, also extensively with e-health. These two programmes are namely the Fifth research and development Framework Programme 1998–2002 and the Sixth Research and Development Framework Programme 2002–2006. However, for the sake of clarity, it must be at this point stated that as the sixth programme is still under implementation the chapter follows the sixth Framework Programme only up to the end of July 2005. Undoubtedly, this means that not the whole range of calls for proposals for projects have been examined. To state it even more clearly, since the 6th Framework Programme and the different calls for it are still in progress there are many initiatives going on in the moment in the field of e-health. Therefore, it has been decided that the core of analysis will be the 5th Framework Programme, yet the analysis touches also with references the 6th Framework Programme as in many aspects the two framework programmes are intertwined.

Still before beginning with the presentation of the 5th and 6th Framework Programmes, the chapter will introduce some general information about the Directorate General of Information Society and Media of the European Commission, as e-health as an area of interest is mainly to be found in this Directorate General. Additionally to the Information Society DG, the Health and Consumer Protection Directorate General is participating and is increasingly taking initiatives in the topic of e-health. In point of fact, there is currently an effort being made to bring together these two DGs in the topics that are of relevance about the development of e-health. How the coordination of e-health looks like currently can be seen in the following figure²⁵.

²⁵ From this figure it is clear that the actions about e-health are a synthesis of many different actors. Thus we can see that mainly two Directorates-General are responsible Health and Consumer Protection (SANCO) and Information Society (INFSO). Nevertheless there is also input from DG Enterprise and Industry, DG Employment, Social Affairs and Equal Opportunities and DG Regional Policy. Moreover there is input from stakeholders representatives and from a proposed interoperability group that provides support on interoperability issues. It should however be noted that this planning is incremental and is still likely to undergo further changes.

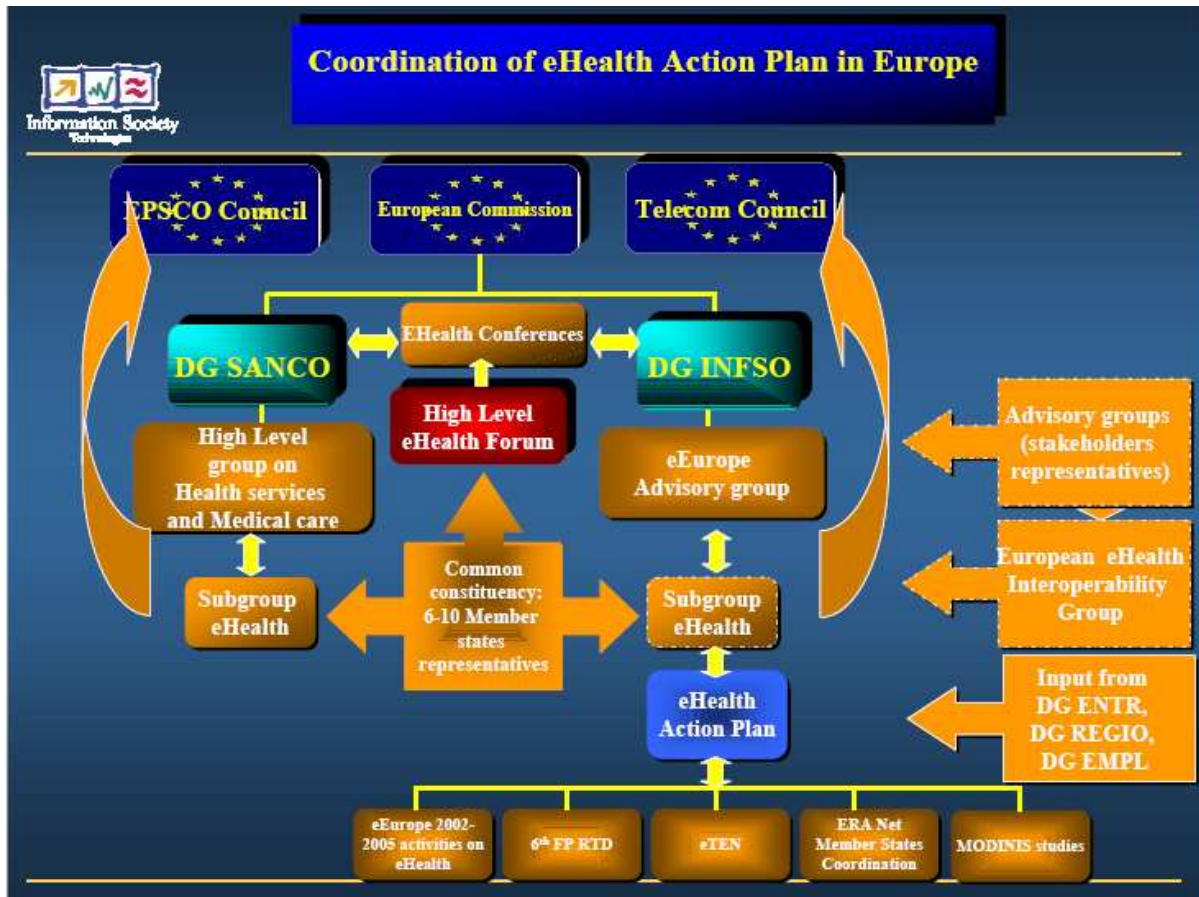


Figure 5.1: the coordination of e-health extracted from the presentation “European Commission Activities in e-health” presented at the “Workshop on Semantic Interoperability” 14-15 February, 2005, Brussels

As a matter of fact, the brand new coordination of e-health as just presented at the EHTEL health care authorities meeting in Den Haag, Netherlands 15.9.2005 and as presented in figure 5.2 has some obvious changes in comparison to the figure representing the coordination plan just nine months ago. In the new scheme, we can observe an increased focus in standardisation efforts (CEN TC 251, ETSI, CENELEC, ISO TC 215, CEN/ISSS) as also the involvement of the stakeholders groups is more highlighted.

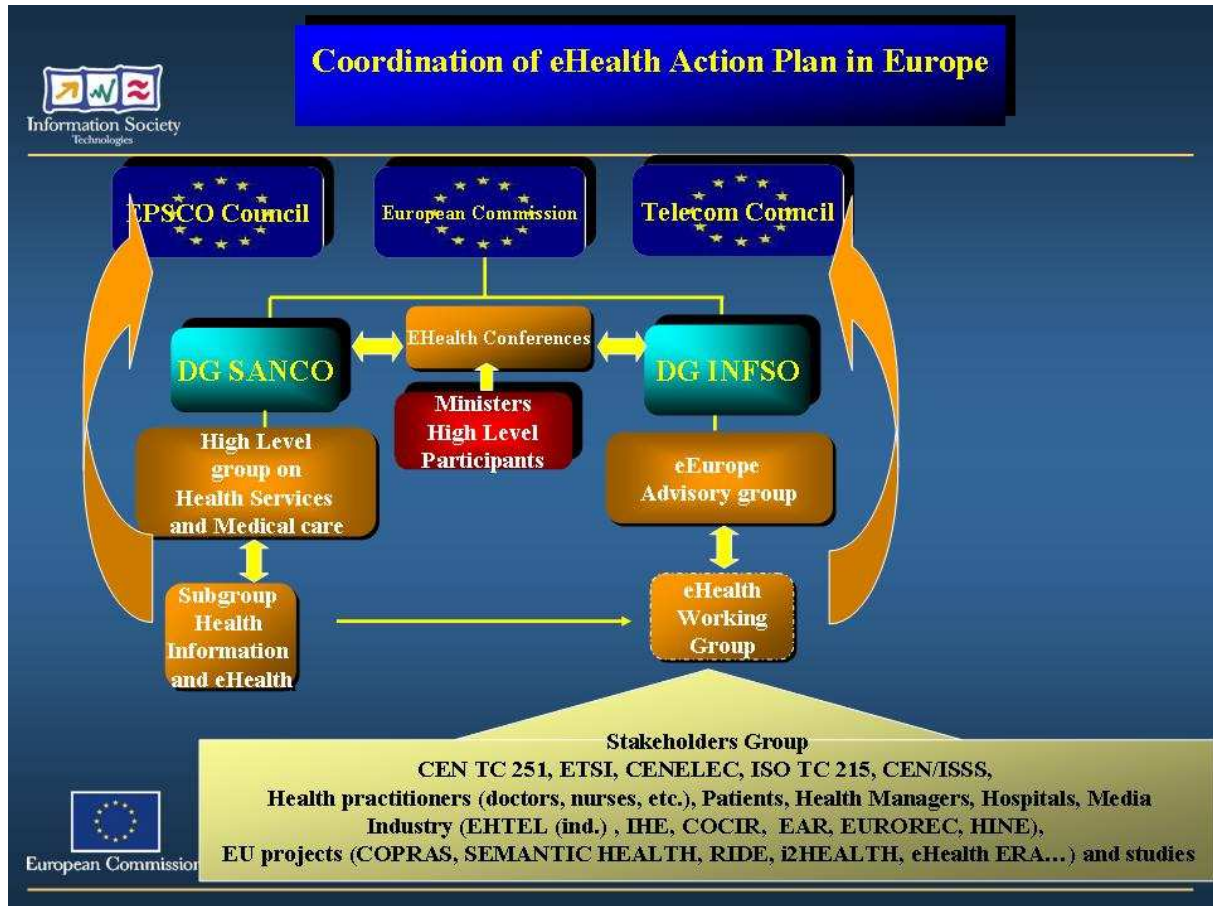


Figure 5.2: the coordination of e-health as presented at the EHTEL health care authorities meeting in Den Haag, Netherlands 15.9.2005

5.1 General information about the Information Society and Media DG

The Information Society and Media Directorate-General of the European Commission is playing a key role in implementing the “vision” set by Europe's heads of state in Lisbon, 2000 of making Europe the world's most competitive and dynamic economy, characterised by sustainable growth, more and better jobs and greater social cohesion, by 2010.

The objectives for the Information Society in the European Union are to ensure that Europe's citizens, governments and businesses continue to play a leading role in shaping and participating in the global information society. In this context, the *eEurope* action plan that was presented in the previous chapter drives the understanding, development and uptake of information and communication technologies and their applications within the European Union.

The DG contributes to these objectives by stimulating research into the development and deployment of new information and communication technologies that can be integrated into citizens' everyday environment, business and administration. Furthermore, the

Information Society and Media Directorate General has established, and is maintaining, a framework of regulation and standards designed to generate competition and stimulating the development of applications and content. At the same time, it supports initiatives that encourage and enable all European citizens to benefit from, and participate in, the information society.

5.2 General information about the 5th Framework Programme

The Fifth Framework Programme (FP5) for Research, Development and Demonstration set out the priorities for the European Union's research, technological development and demonstration (RTD) activities for the periods 1998-2002. It was approved by the European Parliament and the European Council in 1998 and allocated € 14.96 billion and has proved to be a key milestone in the previous years of research and development in the use of information and communication technologies for health.

The research priorities of the Fifth Framework Programme (a synopsis can be found in Appendix 3) were established on the basis of a common set of criteria divided into three categories²⁶, and a multi-theme structure, consisting of seven Specific Programmes, of which four were Thematic Programmes. These thematic programmes were: a) the Quality of Life and management of living resources, b) User-friendly information society, c) Competitive and sustainable growth, and finally d) energy and sustainable development.

Within the framework programme, the IST (Information Society Technologies) Programme focused on research and development activities targeted at “societal problems and needs”. The objective was to realise the benefits of the information society for Europe, both by accelerating its emergence and by ensuring that the needs of both individuals and enterprises are met. The research areas addressed in the IST Programme were organised in four key actions as the following table demonstrates. Nevertheless, in the frame of this thesis, only key action 1 will be thoroughly discussed as it directly connects with the topic of e-health.

²⁶ The criteria were related to the Community “value added” and the subsidiarity principle, in order to select only objectives, which were more efficiently pursued at the Community level by means of research activities conducted at that level. The second set were criteria related to social objectives with the intention of further major social objectives of the Community reflecting the expectations and concerns of its citizens. Finally the third set of criteria was related to economic development and scientific and technological prospects with the purpose of contributing the harmonious and sustainable development of the Community as a whole.

Table 5.1: Information Society Technologies four key actions

| |
|---|
| Key action 1: Systems and services for the citizen. The aim of this key action was to meet policy and user needs and to ease access at the lowest cost to quality general-purpose services, to boost the industry providing these services and to pave the way to ‘digital communities |
| Key action 2: New methods of work and electronic commerce. The aim of this key action was to develop technologies to help companies operate more efficiently and to make commerce in goods and services more efficient and to facilitate improvements in working conditions and the quality of work. |
| Key action 3: Multimedia content and tools. The aim of this key action was to facilitate lifelong learning, to stimulate creativity, to enable linguistic and cultural diversity and to improve the functionality of future information products and services, taking account of user-friendliness and acceptability. |
| Key action 4: Essential technologies and infrastructures. The aim of this key action was to promote excellence in the technologies, which are crucial to the information society, to speed up their introduction and to broaden their field of application. |

In particular, within the first key action, five priority areas were defined. These were *applications relating to health*; persons with special needs, including the disabled and the elderly; public administration; environment, and transport and tourism. Going more into depth in the area of “Applications relating to Health”, three main “societal needs” were clearly identified which are similar to the actors the thesis has identified in the previous chapters.

The first societal need identified is for health professionals. In this category, the key needs are the optimisation of the human, technical and financial resources allocated to the healthcare systems. The second is for citizens, where the key needs are the requirement to stay healthy and to protect general well being. Finally, the last societal need identified is for patients, with the key need being receiving the best possible quality of care. Based on these societal needs the European Commission developed a formal model, which is depicted as a “Flower with 3 Petals” (figure 5.2). Each petal is representative of one of the three main societal needs described above. In the centre of the flower are elements common to all three groups such as the *eEurope* action plans already seen, info-ethics and legal regulation issues. Additionally, some common strategic tasks, referred to as ‘industrial affairs’, include standardisation and certification, as well as implementation and exploitation of research results.

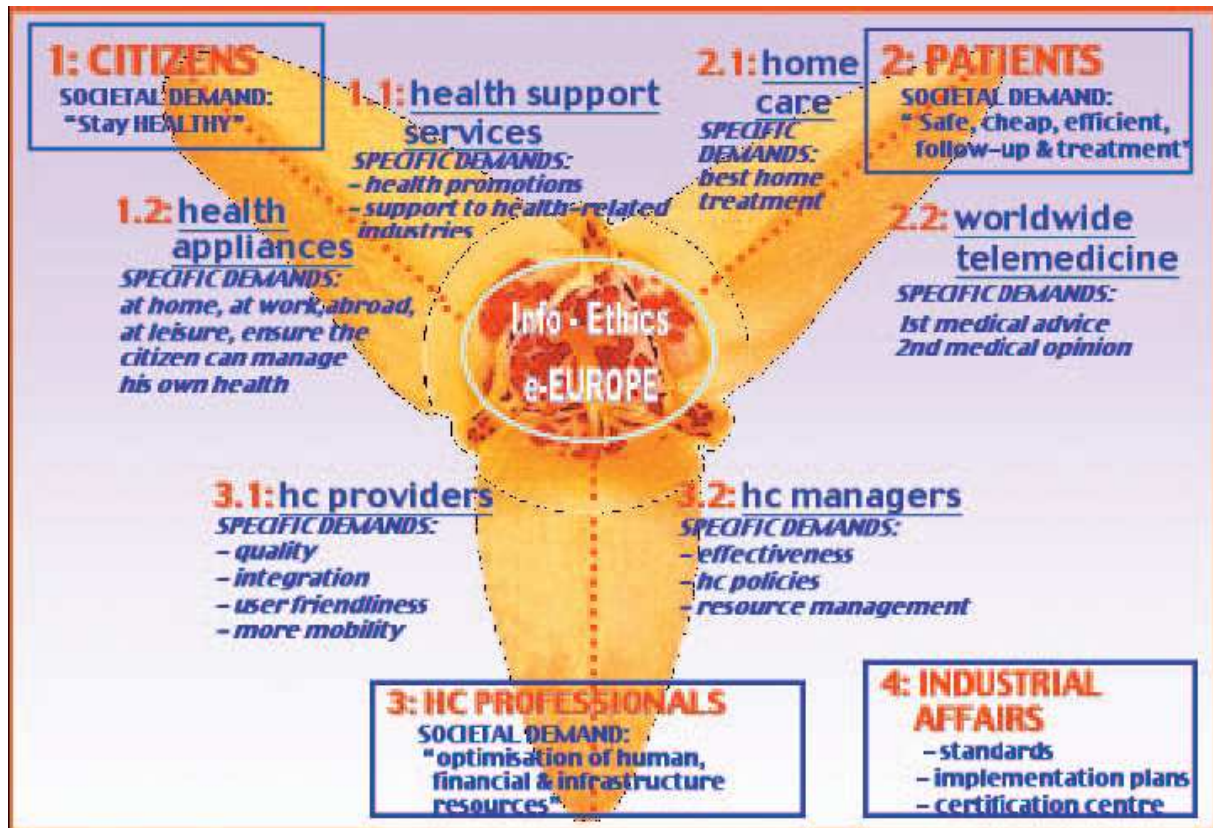


Figure 5.2: Flower model – translating societal needs into actions extracted from Final report (April 2004 edition) Applications relating to health. Fifth research and development framework programme 1998 - 2002

5.3 Programmes of 5th Framework Programme about e-health

In order to optimise the impact of the individual projects and the set of projects as a whole, projects have been grouped into three clusters according to the three main user groups and societal needs (patients, healthcare professionals and citizens). Additionally, the cooperation between these projects within each cluster was strongly encouraged.

The main objective of this clustering was to improve the performance of the individual projects in a given cluster by maximising the possibilities for interaction with other projects and stakeholders in the domain. As it is obvious from the figure, in the projects financed by the 5th Framework Programme there is a differentiation between patients and citizens. Although this might initially appear as a difference towards the actors identified in the previous chapters, this represents, in reality, no problem as until now citizens and patients were identified as one and the same actor, namely patients. Nonetheless, in the context of the 5th Framework Programme there is a need to split patients as identified until now in two actors, as this is more effective and efficient. Through this split of patients and citizens, the Commission is able to identify and finance more specific related projects. This is of course

also a result of the increasingly emphasis given on prevention rather than healing²⁷. Thus, while on the one hand for patients, the key needs are to receive the best possible quality of care in order to overcome their health problem, for citizens, on the other hand, the key needs are the requirement to stay healthy and to protect general well being. Furthermore, fundamentally, the initiative to support citizens in obtaining good quality health information on the internet is based on the recognition that European citizens are avid consumers of health related information and is also a result of the general trend of preventive healthcare. A short overview of each of these clusters is provided in the following subsections.

5.3.1 Intelligent systems for the health professionals

This cluster of projects was aimed at assisting health professionals to cope with major challenges, including enhancement of health services provision and continuous learning and training, through innovative, user-friendly, fast and reliable IST technologies and systems. During the 5th Framework Programme, 75 projects were financed in this cluster for a total of € 76.5 million.

The main research work of the projects covered: new generations of computerised clinical systems, advanced interactive environments for remote and timely access of available best medical practice and patient's medical files from anywhere, collaborative healthcare provision, evidence-based medicine and finally systems supporting continuous education. The added value of the cluster was centred around interoperability, standardisation, clinical validation, awareness and dissemination. The major objective these types of projects implemented, were increasing accuracy and effectiveness of diagnosis and treatment, as well as reducing treatment and waiting time. The results of these projects are expected to have significant impact on saving lives, but have also some economical connotations on the public health domain. They can, on the one side, reduce health expenses in the long run, and on the other side reinforce the European medical equipment industry, which by its turn could lead to an increase in employment, and effectively in growth of this sector of the economy.

²⁷ Here it could be also stated that in general the championed new public health strategies embrace among others health protection, preventive medicine, health education, and community empowerment (Lupton).

5.3.2 Intelligent systems for the patients

This cluster of projects deals with patients. The rationality behind clustering patients is that healthcare providers faced with an ageing population and rapid innovation in medical treatments, are looking for cheaper and more responsive ways of delivering services in contrast to the large, centralised institutions that previously existed. Additionally, a need that has to be fulfilled is that healthcare services have to be accessible to everyone, at low cost, wherever and whenever they need them.

A response to both demands can be best achieved through home-based healthcare, which can be both more comfortable and convenient for patients and less costly for healthcare providers. Furthermore, hospital treatment is in reality the most expensive component of healthcare. In addition, patients often find prolonged hospital stays difficult. Consequently, after four centuries of delivering health care in hospitals, industrialised countries are now shifting towards treating patients at the point of need. The ‘Intelligent Systems for Patients’ cluster was a response to this evolution in health. As the point of need of patients is predominantly their home, this approach is called homecare. Homecare can be defined as a component of medical care where patients unable to reach physically a healthcare provider receive evaluation and treatment in their homes or more extensively at the point of need. During the 5th Framework Programme, 30 projects were financed in this cluster for a total of € 48.5 million of European funding. Obviously, this reinforces the statement made in chapter 2 that we are moving from a centralised healthcare system towards a more individualised based system.

Concluding, this cluster aimed to improve patient care by researching technologies that gives the opportunity for patients to be treated at home without any reduction in the quality of treatment. This is expected to improve the quality of life of patients and additionally saves on hospital resources. Moreover, research in the cluster aimed to increase the efficiency of health delivery by improving the communication between the different professionals involved in the treatment of a patient, thus leading to “continuity of care”.

5.3.3 Intelligent environment for the health of citizens

This cluster of projects was aiming at supporting European citizens to stay healthy by researching IST technologies and systems for health promotion and disease prevention. In particular the cluster targets citizens, including those predisposed to diseases, with high risk factors (such as high cholesterol level, high blood pressure or, if appropriate, genetic profile)

by actively facilitating lifestyle changes. To illustrate, three out of four Europeans die as a result of cardiovascular diseases or of cancer. Research has shown that both diseases can be prevented to a significant extent by adopting appropriate lifestyles. In order to encourage citizens to implement the appropriate lifestyle changes, research was conducted first about innovative, secure and portable health systems which will provide personalised health information and guidance at home, at work or on the move and secondly about health lifestyle related products and services (in domains such as nutrition and physical exercise) that provide/incorporate advice, either embedded or online, from the medical and paramedical professions. The socio-economic challenge for this cluster of projects was to reduce the number of avoidable deaths due to cardiovascular diseases²⁸. Each project chose to focus on a particular factor and through the cluster, it has been ensured that the technologies and systems developed act in harmony. Within the limit of the cluster budget, (€ 48.9 million of European funding for 29 projects), it was envisaged to design a skeleton generic enough to accommodate other types of risk factors and a response to them. The expected impact was the ability to use this result as a lever for other health programmes to join in.

5.4 The 6th Framework Programme

This section of the chapter introduces very briefly some general information about the 6th Framework programme, which is currently under implementation. The activities of the European Commission at this moment have two components that illustrate the continuation principle. The first component is the definition and implementation of a new round of research topics and programmes, and the second one is the support and coordination, at a European level, of the deployment of the results from past research programmes.

On the research side, the first call for proposals for the Sixth Framework Programme included an opportunity for submissions under the strategic objective e-health²⁹. The strategic objective for the 6th Framework Programme covers the following three thematic areas: ubiquitous personal health management systems, new reliable software tools supporting health professionals, and biomedical informatics i.e. synergy between medical informatics,

²⁸ The factors related to lifestyle, which a citizen can act upon, can roughly be categorised into (1) smoking cessation, (2) nutrition, (3) physical exercise, (4) social relationships and (5) environment.

²⁹ As a result of the evaluation of FP6 Call 1, the e-health sector received numerous proposals. A total of 175 proposals were received, for a total cost of over € 1.2 billion and requesting a grant of € 915.1million. Ultimately, 20 proposals were selected for funding. The high oversubscription reflects the high level of interest and expectation that is placed on the new e-health tools for both health professionals and citizens/patients, as well as on the new research domain of biomedical informatics.

bioinformatics and neuroinformatics. Additionally, a second call, Call 4, with another strategic objective on e-health has recently been evaluated, and the proposals that were selected are currently under negotiation. It is anticipated that some 20-25 projects with Commission co-funding *circa* 80 millions euros will eventually be funded.

The general objectives of IST in the 6th Framework Programme are to ensure European leadership in generic and applied technologies at the heart of the knowledge economy. It aims to increase innovation and competitiveness in European businesses and industry and to contribute to greater benefits for all European citizens by placing the user, the individual, at the centre of future developments.

5.5 Synthesis

This chapter had as its goal to examine the implementation of the e-health initiatives undertaken by the European Commission³⁰. In order to achieve this objective, the chapter discussed the two major Framework programmes (5th and 6th Framework Programme) financed by the European Commission that deal among others also extensively with e-health³¹. Nevertheless, as this is far from complete, the next chapter examines in detail some best cases that were financed by the two framework programmes in order to analyse the practical implementation of the different initiatives.

³⁰ For more information about future actions of the European Union please consult Appendix 4 that summarises the action presented in the action plan “e-Health – making healthcare better for European citizens: An action plan for a European e-Health area”

³¹ Here it should be added that also the Health and Consumer Protection Directorate General has an area in its Public Health Programme, which is particularly called ‘health information’ and supports a limited number of e-health-related projects. In summer 2005, some 20 projects were accepted for negotiation under the area of ‘health information’ and to the tune of approximately twenty million euros co-funding.

6 BEST CASES

Abstract

In this chapter of the thesis some selected best cases will be presented. The majority of the cases presented are about citizens and patients and have their focus on prevention. In order to identify some relevant cases the *e*Europe awards of 2004 about e-health have been used as a guideline. Undeniably, many cases all over the European Union are acknowledged as best cases, nevertheless it has been decided that also another certification made by independent experts of the field should be used, in order to guarantee that the cases selected and analysed in this thesis represent also in reality best cases.

The *e*Europe Awards for e-health that were sponsored by the European Commission were presented at the e-health 2004 high-level European conference, held in Cork, Ireland, on 5th -6th May 2004. The winners were chosen from 32 different finalists who exhibited at the conference and which were on their turn selected by a team of independent experts from a total of 109 proposals that were submitted. The selection criteria included the degree of user interactivity, the impact on the organisation, the use of information and communication technologies and the real impact and results of the project. The awards were given in three different categories of projects: e-health information tools and services for citizens; e-health administrative support tools and services for citizens; and e-health homecare and telemedicine tools and services for citizens.

6.1 General Information about the *e*Europe Awards

The *e*Europe Awards are intended to be a driving force in identifying and promoting excellence and creativity in the public sector with a view to supporting the mutual recognition and adoption of best practices. The *e*Europe Awards have aimed to highlight and disseminate efforts made by European national, regional and local administrations in using Information Society Technologies (IST) in order to increase efficiency and performance and to improve the quality and accessibility of public services. The applications submitted for the *e*Europe Awards are evaluated and ranked by an independent jury composed of eminent experts from all over Europe in the relevant fields³².

Thus, as these awards represent excellent quality on the one side, and the projects awarded have been scrutinised as best cases on the other side, it has been decided that it would be wise to use them also in the analysis of this thesis. Additionally, another reason to choose these specific projects was that they are representative of the initiatives undertaken by the European Commission. First of all, they are citizen-centred, and secondly they come from different European countries. Another important motive to use the *e*Europe for eHealth Awards of 2004 about e-health was that in comparison to the exhibitors selected in 2005 these

³² Yet in a change of policy it is anticipated that there will be no further funding of these awards post-2006

were selected by experts on the field and not by the governments of each member state. This has as a consequence, that the sample of the cases is less biased. In this manner, only the best projects are represented and not some specific projects governments promote as best cases.

Besides, as the 6th Framework Programme is currently in progress, it would not be accurate to use it as the core of the analysis as it is still in progress, and projects are still under implementation. Nevertheless, one specific project financed by the 6th Framework Programme will be presented as on the one side it provides an overview of how future projects will look like and on the other side is important both because it has a patient oriented focus and furthermore because it includes all the actors discussed in the thesis. Furthermore, this may help us also draw another potential conclusion or highlight an aspect that may not be so apparent until this point.

6.2 Sundhedsportalen / The Health Portal ³³

The overall winner of the eEurope Awards in the category for “ehealth administrative support tools and services for citizens” was Denmark's national Public Health Portal. The public national health portal (Sundhedsportalen / The Health Portal) is a collaborative project between the Danish Regions (Association of County Councils in Denmark), the Ministry of the Interior and Health, the City of Copenhagen, the Municipality of Frederiksberg, the Copenhagen Hospital Cooperation (H:S) and the Danish National Association of Local Authorities.

The Healthcare Portal brings together the regional information systems for the benefit of citizens, healthcare providers and professionals. Linked to the National Health Data Network and working in collaboration with all Danish health authorities, the portal contains much more than basic information on healthcare provision, a contact directory and information on general health, specific illnesses and their prevention. It also supplies information about rights in the healthcare sector and how to seek legal advice to enforce these if necessary.

The overall purpose of the Health Portal is to support the general aims of Danish National Health Service activities, among which might be mentioned improved information and service, quality assurance and development, along with enhanced utilisation of both treatment and care resources. The Health Portal is intended to give targeted access to the

³³ Based on personal communication through email and press material retrieved from http://dialog.sundhed.dk/Om_sundheddk/Pressematerialer/InEnglish.htm

overall National Health Service, affording users opportunities to gain an insight into their own possibilities and treatment at times when they have information and communication needs. Moreover, the Health Portal is intended to facilitate communications between the parties involved in the National Health Service. In this connection, a crucial success criterion for the Health Portal is to be seen as a tool capable of being integrated into clinical work in such a manner as to allow healthcare professional users to solve those tasks supported by the Portal in a quicker and/or improved manner.

For instance, the portal gives immediate secure web access to details of patient's radiological investigations carried out in any Danish hospital, as well as reports on any laboratory tests that may have been carried out. General practitioners can also order laboratory tests through a centralised online request system. If admitted as an emergency a Danish citizen can rest assured that the doctor treating him or her has access to this vital information. A sub-project focusing on teledermatology provides general practitioners with information about practitioners operating this service and full instructions on how to use it.

In addition to offering a comprehensive service to healthcare professionals, the portal also offers some unique services for citizens. Patients can contact their general doctors for advice using the portal or e-mail at any time of the day or night. Patients can also enter appointments directly into their doctor's diary, which can then be confirmed or rejected by the doctor via the portal. An online prescription renewal service, allows patients receiving homecare or suffering from chronic conditions to renew their prescriptions without attending the surgery. Approved prescriptions will be delivered direct to the pharmacy, which will arrange delivery or collection with the patient³⁴.

Analyzing the project, we can identify that almost all the main actors identified throughout the thesis (patients, government, medical professionals, and industry) are represented in a greater or lesser extent. Since the focus on the selection of the best cases was given in patient oriented projects, it is of course self-evident that patients will be in the core focus of the project. Patients and also citizens can use the system in order to access the Danish health authorities. As the system enables communication and services between health professionals and citizens, the citizens can comfortably book appointments with general practitioners, or even conduct e-mail consultations with their general practitioners or just ask him or her for advice. In this case, it is possible for a patient to send a question immediately when thinking of it, and hopefully get a fairly quick response. Furthermore, chronic patients

³⁴ For more information about the project please consult Appendix 5

may renew their prescriptions regularly, and in many cases, there is no need for a visit to the general practitioner's surgery, which of course is vital in many cases as through such a service patients can save both time and enhance their quality of life especially in cases where people have a disability. What is more, the same applies also with electronic administration of prescriptions. Through this service, the patient does not have to wait for the medication to be administered as upon entry into the pharmacy, the medication has already been prepared. Thus, the patient can go back to work or back to bed much more quickly. Finally, as already stated citizens can find basic information on healthcare provision, a contact directory and information on general health, specific illnesses and their prevention.

On the other hand, besides patients also other actors are represented. For instance, the government as an actor is represented in the organisation of the system first as being the initiator of it, and secondly, as being the actor that constructs and also controls the development of the system. This is done in the sense that the system is used to support the general aims of Danish National Health Service activities, which of course are a governmental responsibility. Thus, being a part of it, it has to follow the development of the whole public health policy.

In addition to the government, the medical and healthcare professionals are also represented in the sense that they can use the system in order to accomplish their work more efficiently and effectively as they can have all the data off the patients almost immediately at hand. In extrapolating this fact, we could use a part of the speech of Mrs Viviane Reding, the European Commissioner for Information Society and Media, in the 2005 high-level conference about e-health. Mrs Reding stated in accordance to using such systems that "electronic medical records can help doctors to diagnose illness and prescribe treatments more accurately, thus reducing medical errors. It also means cutting down paperwork to improve efficiency. Electronic patient referrals in Denmark are saving 1 million euro a year and could rise to 3.5 million euro a year, if all referrals were sent electronically." However, this kind of initiative is not only about reducing costs, but it is merely about the fact that these funds can be used in actual treatment and not on the paperwork, that accompanies treatment.

Using the approach, already used in previous chapters, we could summarize the findings in the following table

Table 6.1 Sundhedsportalen / The Health Portal

| | |
|-----------------|---|
| Context | Patient-Citizen oriented e-health administrative support tools and services. Funded by the Danish Regions, the Ministry of the Interior and Health, the City of Copenhagen, the Municipality of Frederiksberg, the Copenhagen Hospital Cooperation and the Danish National Association of Local Authorities. In fact the Danish Regions has paid the majority of the establishing costs - the regions pay the majority of the yearly fees, however all owners pay a smaller share. |
| Fact | Patient-Citizen oriented e-health administrative support tools and services. The citizen-patient has the opportunity to comfortably book appointments with general practitioners, or conduct e-mail consultations with their general practitioners or ask them for advice. Chronic patients may renew their prescriptions regularly. Finally, citizens can find basic information on healthcare provision, a contact directory and information on general health, specific illnesses and their prevention. |
| Analysis | Fundamental involvement of both users and public partners. Iterative process with ongoing involvement from the actors. However, the focus is on the citizen and the patient and the main goal is providing patient related services. The different actors (minus the industry) have a big share of the success. More than 650 editors in the regions and national authorities. In addition, there are different forums where e.g. the medical professionals share their view on the project. In that way, it is a very decentralised project. The system developments are still under progress. |

6.3 WRAPIN - Worldwide online Reliable Advice to Patients and Individuals

The overall winner in the 2004 category for “ehealth information tools and services for citizens” was Switzerland’s Health on the Net Foundation. This was an initiative that had previously received co-financing under the 5th Framework Programme. The project was called WRAPIN (Worldwide online Reliable Advice to Patients and Individuals).

The “Health on the Net Foundation” has developed and implemented services to guide the growing online community of healthcare consumers and information providers to sound, reliable medical information and expertise free of any commercial influence. Its key service is a code of ethical for website operators providing online health information, currently in use by 3,600 websites. The services available by this network include an accreditation system for websites and a search engine/directory of trustworthy information sources available to all citizens. The WRAPIN system financed by the 5th Framework Programme helps solve two major problems faced by citizens in their search for medical and health information. The first is how to find information among a large number of potentially useful documents and the second is to evaluate the relevance of an online medical document.

Regardless of the improved access to information made possible by the Internet, it remains extremely difficult to judge the trustworthiness or relevance of online content. Mutually professionals and citizens face this problem, which can be of critical importance in the case of health related information. WRAPIN aims to support citizens with practical,

convenient solution to the problem of large numbers of documents of uncertain quality by providing a wide range of trustworthy medical and health content.

The system will offer a modular platform to interconnect the most trustworthy and complete information sources. Until now, it contains MEDLINE (scientific medical articles from the nineteen sixties through to the present), Clinical Trials, OESO (a new electronic database prepared for the World Organisation for Special Studies on Diseases of Oesophagus, Urofrance (French urology database), MedHunt (medical search engine) and finally the HON code of conduct accredited Web sites. The system has as its goal to provide also an entirely new service enabling the comparison of health/medical documents with the interconnected knowledge base. In this way, it will discover if the information exists in the published literature and thus will help to determine the reliability of documents by checking the ideas contained against established benchmarks, and enable users to determine the relevance of a given document from a page of search results³⁵.

Analyzing the project, we can identify that the core focus of the project is the citizen and that the objective is to make him or her more confident about using health related information that can be found in the network. The approach to fulfil this is by assuring that the information available is trustworthy. It could be actually stated that the project aims to use the already developed network as a centre that will be used by the citizen and the patients to gain online reliable, trustworthy advice about all medical related questions. In reality, as citizens are increasingly seeking more and more reliable and trustworthy medical and health care information, WRAPIN offers the capacity to reply with synthetic information in the search query³⁶.

In addition to citizens and patients, also other actors are represented. For instance, government as an actor is not directly represented in the organisation of the system, as the Health On the Net Foundation (HON) is an international non-governmental organisation established in Geneva. Nevertheless, we could state that the government is represented indirectly as on the one side WRAPIN is financed by the 5th Framework Programme and on a second level the French Ministry of employment and solidarity through its mission for informatization of health systems (MISS) participates in the development of the project. Furthermore, also the medical and healthcare professionals are represented in the sense that the system uses the expert knowledge they have and is already registered in the database.

³⁵ Based on the Final report - Public version "Worldwide online Reliable Advice to Patients and Individuals" retrieved from http://www.wrapin.org/E180_Conference_publication.htm

³⁶ This means that it provides a complete answer combing different information sources

Table 6.2 Worldwide online Reliable Advice to Patients and Individuals

| | |
|-----------------|--|
| Context | Providing access to scattered/invisible (those not hyperlinked from online public documents) trustworthy medical databases to help patients, citizens and professionals better judge the quality of information available on the Internet. The system is built using the tools, experiences, databases and expertise of each of the members of its network. Aim is to help in the formulation of more efficient medical queries and facilitate access to multiple knowledge sources. |
| Fact | Tool to determine information quality by automatically checking a document against matching sources from databases of known quality. Reassuring the patient by comparing the information found to professional expertise and thus guaranteeing the relevance of the information acquainted. |
| Analysis | WRAPIN is based on the HON tools and ARIANE (Prototype system which allows making conceptual queries to medical information databases) In addition to the HON regularly used databases such as those from MedHunt (web sites), HONSelect (conferences, images and news) and HONcodeHunt (Accredited Web sites by HON) WRAPIN integrates professionals, scattered and invisible databases such as Medline, Clinical Trials, FDA drug information, Vidal, URO and OESO. In an environment where patients and individuals are seeking more and more reliable and trustworthy medical and health care information, WRAPIN replies with providing synthetic information, which can be found in trustworthy medical databases. In this way, the system helps patients, individuals and professionals to better judge the quality of information available on the Internet. |

6.4 MyHeart³⁷

MyHeart is an Integrated Project of the 6th Framework Programme under the leadership of Philips, aiming to develop intelligent systems for the prevention and monitoring of cardiovascular diseases. The project develops smart electronic and textile systems and appropriate services that empower the users to take control of their own health status. Its focus is on the prevention of cardiovascular diseases. Cardiovascular diseases (CVD) are the leading cause of death in developed countries. This disease class includes myocardial infarction, congestive heart failure, arrhythmias and stroke. Over 20% of the European citizens suffer from chronic CVD, while 45% of all deaths in Europe are due to CVD. Europe spends annually, hundred billions of Euros on the treatment of CVD. In addition to the present situation, Europe faces with the upcoming aging population the challenge of delivering high-quality healthcare to its citizens at affordable cost. Although it is widely accepted that healthy and preventive lifestyle, together with early diagnosis, could systematically fight the origin of CVD, for cost-related reasons institutional points of care can currently offer only intermittent episodic treatment. (IST 2004: Participate in your future)

³⁷ Based on information of the Information Society and Technology booklet IST 2004: Participate in your future, the internet webpage: "Healthcare from a different perspective" retrieved from <http://www.design.philips.com/about/design/newvaluebyonedesign/section-13665/index.html> and personal contact.

The mission of MyHeart is to empower citizen to fight cardio-vascular diseases by preventive lifestyle and early diagnosis. The starting point is to gain knowledge on a citizen's actual health status. To gain this info continuous monitoring of vital signs is mandatory. The approach is therefore to integrate system solutions into functional clothes with integrated textile sensors.

The idea behind MyHeart is to apply continuous or periodic monitoring of vital signs, in order to gain knowledge about a person's health status. To achieve this, MyHeart integrates functional clothes with on-body sensors (textile and nontextile) and electronics into the so-called *intelligent biomedical clothes*. These are capable of acquiring, processing and evaluating physiological data. The results are sent via a wireless personal area network to a mobile phone or PDA and from there to a server farm, which offers professional medical services. Depending on the diagnosis, recommendations are given to the citizen. In this way, the full functionality of the MyHeart system is realised. (For more information about the project, see Appendix 6)

The key scientific objective of MyHeart is to motivate the citizen to adopt a healthier lifestyle and to use the MyHeart system. The project is expected to show the medical effectiveness and demonstrate cost benefits compared to the classical health delivery system. Furthermore, it is expected that the project will show the medical effectiveness and will demonstrate cost benefits compared to the classical health delivery system. The MyHeart project starts from the application point of view. Five application clusters have been identified: Cardio-Active, Cardio-Sleep, Cardio-Relax, Cardio-Balance, and Cardio-Safe. These five application clusters are tackling the addressed risk factors inactivity, sleep disorders, stress, inadequate nutrition that can be fought by prevention and the detection of acute events such as heart attack.

Additionally, MyHeart, with its innovative system-solutions for personalised care, is promoted by the European Union as having the potential to modernise the European healthcare system and enable it to cope with future demographic challenges. Moreover, the system contributes to the European excellence in the area of biomedical engineering, and is expected to provide the opportunity for the European industry to position itself as the leader in this field. On a social level, by empowering the citizens to take control of their own health status, MyHeart will offer them the opportunity to enjoy better quality of life and higher level of social integration and interaction.

Analyzing the project, we can identify that all the main actors are represented. Here the leader of the project, the initiating actor, is the industry. Actually, the 33 participating

organisations range from larger industrial concerns like Philips and Nokia to universities, research institutes and hospitals. “Philips Design is coordinating the business assessment aspect of the project,” says Ms. Deetman, Research Program Manager at Philips Design, “helping the project to move from customer insights to market differentiators. We are also involved with diagnostic clothing and user interaction issues.” A question that could be asked is why Philips, for example, is interested in such a project. Ms. Deetman states that the goal is that a number of commercially viable products and solutions that address the emerging issues in healthcare will be on the market in the coming years. Additionally, Mr. Parameswaran states that he “as theme leader for Personal Healthcare in the Philips Design New Solutions Development Program, analyses how research insights from projects like MyHeart can inform the personal healthcare business strategies of Philips divisions. There is a spectrum that runs from the medical/functional type of solutions typical of Philips Medical Systems to Domestic Appliances and Personal Care consumer health & well-being oriented products, as well as the lifestyle-based propositions that might be offered by Consumer Electronics. Thus, it can be understood that Philips invests in such a project in order to gain further specialisation and also to find new market possibilities.

Although the industry is the initiating actor, nevertheless, the patients as the final users of the product are also on the core focus of the project. As already stated, the mission of MyHeart is to empower citizen to fight cardio-vascular diseases by preventive lifestyle and early diagnosis. Therefore, the starting point is to gain knowledge on a citizen’s actual health status. Thus, the system uses the raw data transmitted by the patient’s body and then returns to him/her actual advices of what he/she should take care of. Moreover, the company stated that the patients are very important and therefore they have carried out an intensive concept testing³⁸ that has led to a finalisation of the concepts to be pursued in the remainder of the project. In addition to patients, the medical and healthcare professionals are also represented. The doctors ultimately are the actors that provide their professional advices, which should be used by the patient to protect their health. Additionally, the doctors can use the system in order to accomplish their work more efficient and effective as they can have all the data from the patients almost immediately at hand.

Finally, the government participates as an actor in such type of projects mainly in order to ensure that the concept of preventive healthcare, which can simultaneously save lives

³⁸ The company carried out an intensive concept testing of 16 concepts and 10 users as well as 5 professionals involved per concept. The tests were carried out in the form of individual interviews of 1 hour duration each. Based on the test results, 4 concepts were formed, to be pursued in the remainder of the project

and cut costs occurred through treatment, establishes to a greater extent³⁹. What is more, as the government has to ensure not only the current health of its population but also to guarantee that economic welfare will exist in the future in order to have the resources needed to finance its social welfare policies, it needs to invest money now in fields where it can have a better pay-off in the future. This type of projects can contribute to the European excellence in the area of biomedical engineering, and are expected to provide the opportunity for the European industry to position itself as the leader in this field. This, in turn, is based on pure economical reasoning, results to more capital influx growth, which will enable the government to invest more in social policies.

In point of fact, it is expected that the final outcome of the system will open up a new mass market for the European industry while at the same time it will reduce the overall EU healthcare costs. The findings of the case analysis can be seen in the following table

Table 6.3 MyHeart

| | |
|-----------------|---|
| Context | MyHeart is based on the development of intelligent biomedical clothes for preventive care application tailored to specific user groups. In order to focus on the user motivation and the individual benefit, MyHeart has defined the main objectives along 5 different application areas. These application areas reflect the main risks for developing a CVD and address the user need for early diagnose to limit the severity of an acute event. The five identified applications are: CardioActive: Reduce inactivity CardioSleep: Improve sleep quality CardioRelax: Reduce stress CardioBalance: Reduce overweight CardioSafe: Reduce morbidity by early diagnosis |
| Fact | The key challenges for lowering the mortality rate in CVD and their related costs are by successful guiding, informing and motivating the citizen to adapt to a permanently healthier lifestyle and the early diagnosis of acute events. The aim of the project is to develop innovative, personalised, easy-to-use solutions and tools, which help the citizen to adopt permanent healthier lifestyle. Therefore, it gathers in a first level data from various target groups, such as heart attack patients, diabetics and those with a higher risk of cardiovascular problems through obesity or an unhealthy lifestyle. |
| Analysis | The system is a new approach financed by the 6 th Framework programme towards developing ubiquitous personal health management systems. The starting point of the system is to gain knowledge on a citizen's actual health status and therefore the continuous monitoring of vital signs is mandatory. This is done by integrating system solutions into functional clothes with integrated textile sensors. The processing consists of making diagnoses, detecting trends and react on it. Together with feedback devices, able to interact with the user as well as with professional services, the MyHeart system is formed. The system is suitable for supporting citizens to fight major CVD risk factors and help to avoid heart attack, other acute events by personalised guidelines and giving feedback |

³⁹ In reality most of us have heard the sentence "An ounce of prevention is worth a pound of cure" which exists actually in most languages for example in German "Vorsicht ist die Mutter der Weisheit". Preventive healthcare thus applies upon this generally accepted phrase

6.5 Synthesis

Concluding, it could be stated that all the best cases presented and analysed in this chapter show the ongoing development of e-health in the European Union. The cases presented have been selected with certain prerequisites. These were that first of all, the cases analysed would be also in reality the best cases. In order to guarantee this, the eEurope Awards for e-health were used as a certification as on the one side the certification is made by independent experts of the field. On the other side, they are sponsored by the European Commission. A second prerequisite was that all the actors identified previously in the thesis should be involved. Nonetheless, the focus should be on patient related cases and on preventive medicine. Finally, a third prerequisite was that also different type of projects based on different Framework Programmes showing the evolution should be used. Therefore, the first case namely Sundhedsportalen / The Health Portal is not an EU financed project. However, it is a certified best case representing also local initiatives and with the continuous iteration of the actors. The second case was WRAPIN, which is an addition to a current system (HON) that has been awarded. The project was co-financed under the 5th Framework Programme and is actually a network of different e-health websites. Finally, the third case analysed shows future initiatives in the field of e-health and is financed by the ongoing 6th Framework Programme. The interesting part in this case is the importance of industry and what we can actually observe is that industry drives the development, taking into account future potential markets and potential uses.

Additionally, it could be stated in order to make a connection to governance, that this approach is part of the systemic rationality that grew in importance after the publication of the final report “Technology in a changing world”, (OECD, Paris, 1991) of the OECD Technology/Economy Programme. This systemic rationality approach can be identified to exist in innovation policies and has become “quite influential in the Nordic countries, especially in departments for industrial development, research and regional development” (Per Koch and Juha Oksanen (eds.). STEP - Centre for Innovation Research, 2003). This type of rationality is based on a systemic view of reality. “Innovation is born out of the interplay between companies and other institutions in so-called national systems of innovation. Innovation is not primarily a result of science push. Instead, the technological development is driven by the companies’ need to survive in a harsh environment (the market). Companies that are able to take part in efficient networks and develop their learning capabilities are more likely to survive” (Koch, Oksanen, 2003, p61). The problem however, that arises again is:

how to involve the final users? How to institutionalise their opinions and thoughts, not only for an advisory role, but for an active participatory role?

7 CONCLUSION

Preface

The purpose of this thesis was to examine and analyse the development of e-health in the Europe Union. This thesis tried to examine how e-health is developed in a policy level, which are the actors that can be identified in the policy level, and finally examined how these policies were implemented in reality through some best cases. The thesis had as its objective to answer questions of who are acknowledged as relevant actors of e-health both in a policy level and in a real life case level, if the patients for whom the technology is intended are involved and so forth. Furthermore, in a more undersized abstract/theoretical level the thesis discussed the changes in the concepts of health as a change in power and examined the development of e-health as part of a more systemic change, namely the movement from a predominantly centralised system towards a more individualised/personalised system.

7.1 Findings

Concluding this thesis, it is time to present the findings that can be observed in the development of e-health. The first remark that can be made is that in the last years, an increasing tendency to include the patients/citizens in the development of e-health can be observed. Thus, we are able to see that the patient, as an actor in the healthcare system, is empowered, also as a result of the move from a centralised towards a more individualised/personalised healthcare system. Additionally, comparing to the past, or better said comparing to the first phases of the evolution of the e-health concept, a move from an economic approach towards a more (compared to the past) patient oriented focus is rather clear illustrated both in terms of polices and of real cases.

Nevertheless, as also the MyHeart case, but also the initial development showed, when a new technology is introduced the most important actor is the industry, as it is the primary actor and that is due to the fact that infrastructure has to be built. Generalising this approach, we could actually observe the policy followed most of the times today and which has two major phases.

The first phase is when technology is new. In the promotion of a new technology, the rationality that can be mainly identified is the economic one. This results also from the fact that the government or the state does not perceive each policy area on its own but in an interaction, (it does not concentrate on only one policy, but tries to form a basket of policies)

and tries to structure the framework so as to be able to achieve the general goals set. Taking this into account, technology can cut on the one side costs, and on the other side increase efficiency, and efficacy and provide new opportunities to develop the industry. This in turn can lead to more employment that can eventually lead to growth of the economy, which will at the end result in a better socioeconomic environment⁴⁰.

The second phase is when the technology stabilizes and is ready to be widely used. By then, we have a change in the most important actor, with an increasing involvement of the final users. The final users become more important, the applications are developed with their help, either through an iterative process, or through expressing their opinion about what should be the actions that follow, and what should be the requirements of new products. However, it must be here stated that this whole approach is based on systemic rationality. Thus, the final users are under the systemic rationality, which is predominant in the technological system.

In this manner, the framework looks like following. The state introduces new technology in collaboration with companies with the scope of cutting costs, improving efficiency, gaining competitive advantage⁴¹ in comparison to other states and finally by a synergy of all of them steering growth. Once the technology and its infrastructure are in place, then the consumers come to the front mainly as the end users/buyers of the final products. This is a result on the one side of the fact that these services are in the form of public goods provided by the state to its citizens and secondly are influenced by the reality that investments must be utilized in their full potential in order to have the results envisaged/calculated in the beginning and thus remain viable. Furthermore, what has to be explicitly stated and therefore is emphasised, is that governments, especially in the industrialized countries, tend to see technological investments as the only way to keep up their growth rate and survive the competition between states in a globalised world as they are not able to compete in forms of less cost strategies.

In the case of e-health, the first step towards its introduction was a technological investment, namely, on telecommunications. In the same time, also due to the fact of the movement of the general healthcare policy towards treating health as a commodity, but also due to an increasing individualisation, the investment seems very promising as it cuts costs down and on the same time it improves the quality of life of patients and citizens and of

⁴⁰ Under the perquisite that growth is transferred to the whole society.

⁴¹ Knowledge (technological knowledge) and skills are a major source of competitive advantage accumulated through learning processes.

course saves also others humans lives. So, we can see that both partners represented in the systemic rationality, companies and the state through so-called national systems of innovation, are better of.

Additionally, the development of e-health in the European Union, due to the establishing Treaty through which health is currently a Member State responsibility, could deal with the subject only under an economic logic and this is not the first time that this approach is used. In cases where the Commission has not the responsibility (like the health sector), the articles that are used to initiate some activities and to find some common ground are the articles of the Internal Market. In the case of the development of e-health, this can be observed also by the development and its positioning in a given Directorate General (DG).

Accordingly, at first e-health was a part of the Enterprise and Industry DG, in the end of the nineteen nineties it was part of the Enterprise and Information Society DG; in the last years, it has become part of the Information Society DG – which in turn is latterly the Information Society and Media DG – but with an ever increasing collaboration with the Health and Consumer Protection DG.

Concluding, the questions that arise here are: Could the development of e-health in the European Union could have been different if there were more collaboration between countries in the health sector? Alternatively, what would have happened if the initial mode of collaboration had been founded not only on the Enterprise DG but also in collaboration with the Enterprise DG, because of the necessary infrastructure and of the Health DG⁴², as e-health deals primarily, and for the most, with health?

7.2 Critical remarks

Now that we have seen the landscape and have posted some critical remarks, it is important to focus on some of them, as they are important if we want in the future to have a better policy not only in this topic, but also generally. First of all, the initial problem that can be identified is that a problem of preconceptions exists. Actually, two main preconceptions can be identified in the case of e-health. The first is that of technological determinism, which especially in the topic under consideration is very important. Furthermore, the treatment of patients as mere customers is ethically not correct. The second preconception is that of

⁴² Although the Health Directorate was established in 1999 European action programmes aimed specifically at improving public health throughout the Union have existed since 1987 or in a more concrete form since 1993 when the first Health framework was published.

systemic rationality, which is mainly used in innovation strategies, today. The problem that this poses is that the citizen has not an overview of the rationality behind the innovations and additionally has not a real influence, also in the situations where his opinion is asked.

These two preconceptions lead us to the main problem/question, which is: What is a possible alternative to the current evolution? Why the effect of using a system, especially when no other possible alternative is presented, signifies that this system is the best? Is it the best because it is used? No, this cannot be the answer to the question as essentially no other alternative is presented. A possible answer to this problematic is to try to involve the citizens in the whole process more. This means to inform them more about the proposed innovations and alternatives and ask them about their opinion⁴³. Even more invite them to be directly involved in the whole process⁴⁴; even try, as a possible solution to the problems, to institutionalise the involvement of the citizens. Finally, it could be stated that this institutionalisation of the role of citizens could be a solution not only in the case of e-health, but additionally in the whole question of governance and citizen participation.

⁴³ Democratic and participatory governance based on the will of the people may lead to more responsive and effective government. A trend that can be observed in the last years is the decline in trust of the public towards government. This is a result of many factors; nonetheless, what citizens want and what a good governance should aim for, especially in the information age we are living, is: increase in trust and accountability, more legitimacy of the actions of the government and also more clear communication for the reasons a policy approach is chosen rather than another. This on its turn, presupposes that before the final decision is actually made different alternatives are presented to the citizens

⁴⁴ Yet, this touches another important problem which our democratic system today faces namely if in reality equitable access as also effective representation of all voices in the decision making process exists.

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APPENDICES

Appendix 1

PUBLIC HEALTH

Article 152

1. A high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities.

Community action, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education. The Community shall complement the Member States' action in reducing drugs-related health damage, including information and prevention.

2. The Community shall encourage cooperation between the Member States in the areas referred to in this Article and, if necessary, lend support to their action.

Member States shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1. The Commission may, in close contact with the Member States, take any useful initiative to promote such coordination.

3. The Community and the Member States shall foster cooperation with third countries and the competent international organisations in the sphere of public health.

4. The Council, acting in accordance with the procedure referred to in Article 251 and after consulting the Economic and Social Committee and the Committee of the Regions, shall contribute to the achievement of the objectives referred to in this article through adopting:

- measures setting high standards of quality and safety of organs and substances of human
- (a) origin, blood and blood derivatives; these measures shall not prevent any Member State from maintaining or introducing more stringent protective measures;
- (b) by way of derogation from Article 37, measures in the veterinary and phytosanitary fields which have as their direct objective the protection of public health;
- (c) incentive measures designed to protect and improve human health, excluding any harmonisation of the laws and regulations of the Member States.

The Council, acting by a qualified majority on a proposal from the Commission, may also adopt recommendations for the purposes set out in this article.

5. Community action in the field of public health shall fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care. In particular, measures referred to in paragraph 4(a) shall not affect national provisions on the donation or medical use of organs and blood.

Appendix 2

CHAPTER V AREAS WHERE THE UNION MAY TAKE COORDINATING,
COMPLEMENTARY OR SUPPORTING ACTION
SECTION 1 PUBLIC HEALTH
Article III-278

1. A high level of human health protection shall be ensured in the definition and implementation of all the Union's policies and activities.

Action by the Union, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to physical and mental health. Such action shall cover:

(a) the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education;

(b) monitoring, early warning of and combating serious cross-border threats to health.

The Union shall complement the Member States' action in reducing drug-related health damage, including information and prevention.

2. The Union shall encourage cooperation between the Member States in the areas referred to in this Article and, if necessary, lend support to their action. It shall in particular encourage cooperation between the Member States to improve the complementarity of their health services in cross-border areas.

Member States shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1. The Commission may, in close contact with the Member States, take any useful initiative to promote such coordination, in particular initiatives aiming at the establishment of guidelines and indicators, the organisation of exchange of best practice, and the preparation of the necessary elements for periodic monitoring and evaluation. The European Parliament shall be kept fully informed.

3. The Union and the Member States shall foster cooperation with third countries and the competent international organisations in the sphere of public health.

4. By way of derogation from Article I-12(5) and Article I-17(a) and in accordance with Article I-14 (2)(k), European laws or framework laws shall contribute to the achievement of the objectives referred to in this Article by establishing the following measures in order to meet common safety concerns:

(a) measures setting high standards of quality and safety of organs and substances of human origin, blood and blood derivatives; these measures shall not prevent any Member State from maintaining or introducing more stringent protective measures;

(b) measures in the veterinary and phytosanitary fields, which have as their direct objective the protection of public health;

(c) measures setting high standards of quality and safety for medicinal products and devices for medical use;

(d) measures concerning monitoring, early warning of and combating serious cross-border threats to health.

Such European laws or framework laws shall be adopted after consultation of the Committee of the Regions and the Economic and Social Committee.

5. European laws or framework laws may also establish incentive measures designed to protect and improve human health and in particular to combat the major cross-border health scourges, as well as measures which have as their direct objective the protection of public health regarding tobacco and the abuse of alcohol, excluding any harmonisation of the laws and regulations of the Member States. They shall be adopted after consultation of the Committee of the Regions and the Economic and Social Committee.

6. For the purposes of this Article, the Council, on a proposal from the Commission, may also adopt recommendations.

7. Union action shall respect the responsibilities of the Member States for the definition of their health policy and for the organisation and delivery of health services and medical care. The responsibilities of the Member States shall include the management of health services and medical care and the allocation of the resources assigned to them. The measures referred to in paragraph 4(a) shall not affect national provisions on the donation or medical use of organs and blood.

Appendix 3

Synopsis of the 5th Framework Programme

Summarizing, in the 5th Framework Programme, information technologies for applications related to health have been financed to support citizens, patients and health professionals in their activities, anywhere and at any time. Based on the principle of citizen-centred care the 135 projects have been financed by the “Applications Relating to Health” Unit for a total of € 174 million. The portfolio of projects covered a complementary set of activities, ranging from Research and Technological Development to Take-up actions. It brought together a wide range of researchers, engineers and users from some 750 different organisations spread between industry, with a large participation of small and medium-sized enterprises, and academia, from over 35 countries, building therefore a research community of more than 3500 persons.

Appendix 4

Communication from the Commission to the Council, the European parliament, the European economic and social committee and the committee of the regions. “e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area”. COM (2004) 356 final.

Annex

| Issue 1: Addressing common challenges | Time | Responsibility |
|---|-------------|---------------------------|
| By mid 2005, the Commission should produce a summary of European best practices as guidance for Member States. | Mid 2005 | Commission |
| By end 2005, each Member State is to develop a national or regional roadmap for e-Health. This should focus on deploying e-Health systems, setting targets for interoperability and the use of electronic health records, and address issues such as the reimbursement of e-Health services. | End 2005 | Member States |
| By end 2006, Member States, in collaboration with the European Commission, should identify a common approach to patient identifiers. This should take account of best practices and developments in areas such as the European Health Insurance Card and identity management for European citizens. | End 2006 | Member States, Commission |
| By end 2006, Member States, in collaboration with the European Commission, should identify and outline interoperability standards for health data messages and electronic health records, taking into account best practices and relevant standardisation efforts. | End 2006 | Member States, Commission |
| By end 2006, a collaborative approach should be undertaken among Member States to supporting and boosting investment in e-Health. | End 2006 | Member States |
| By end 2007, Member States should adopt conformity testing and accreditation schemes following successful best practices. | End 2007 | Member States |
| During the period 2004-2008, Member States should support deployment of health information networks for e- Health based on fixed and wireless broadband and mobile infrastructures and Grid technologies. | 2004 - 2008 | Member States |
| By end 2009, the European Commission, in collaboration with Member States, should undertake activities to: Set a baseline for a standardised European qualification for e-Health services in clinical and administrative settings. Provide framework for greater legal certainty of e-Health products and services liability within the context of existing product liability legislation. Improve information for patients, health insurance schemes and providers regarding the rules applying to the assumption of the costs of e-Health services. Promote e-Health with a view to reducing occupational accidents and illnesses as well as supporting preventive actions in the face of the emergence of new workplace risks. | End 2009 | Commission, Member States |

| Issue 2: Pilot actions: accelerating beneficial implementation | Time | Responsibility |
|---|-------------|---------------------------|
| <p>By end 2005, a European Union public health portal will give access to European level public health information. Health portals shall offer dedicated information on safety at work and health risks in the workplace.</p> <p>By end 2005, there will be a strengthening of early warning, detection, and surveillance of health threats through enhanced information and communication technologies tools.</p> | End 2005 | Commission |
| <p>Promoting the use of cards in the health care sector. Adoption of implementation of an electronic health insurance card by 2008.</p> | 2008 | Commission, Member States |
| <p>By end 2008, the majority of European health organisations and health regions (communities, counties, districts) should be able to provide online services such as teleconsultation (second medical opinion), e-prescription, e-referral, telemonitoring and telecare.</p> | End 2008 | Member States |
| Issue 3: Working together and monitoring practices | | |
| <p>In 2004, a high-level e-Health forum should be established, the role of which will be to support the Commission services. It should involve all necessary stakeholders, including at national, regional, or local hospital authority levels, thereby enhancing the understanding of the Commission services with regard to the current and planned status of development of e-Health in Member States. Its task should be to follow up the various roadmaps, and to identify further actions including a strong focus on users and access for all to e-Health, as well as to develop a strong evidence basis for the case for e-Health. The work of the e-Health forum will also be closely associated with the implementation of the Community Public Health Programme.</p> | May 2005 | Commission |
| <p>By the start of 2005, Member States, in collaboration with the European Commission, should agree on an overall approach to benchmarking in order to assess the quantitative, including economic, and qualitative impacts of e-Health.</p> | Start 2005 | Member States, Commission |
| <p>By the end of 2005, the European Commission, with contributions from Member States, should establish an effective way of disseminating best practices and supporting actions within the European e-Health area.</p> | End 2005 | Commission, Member States |
| <p>An assessment of e-Health developments should be completed ahead of the second part of the World Summit to be held in Tunis in 2005.</p> | 2005 | Commission, Member States |
| <p>During the period 2004-2008, Member States with the support of the European Commission will organise special events such as high-level conferences in order to disseminate best practices.</p> | 2004-2008 | Member States, Commission |
| <p>During the period 2004-2010, every two years, the European Commission will publish a study on the state of the art in deployment, examples of best practices, and the associated benefits of e-Health.</p> | 2004-2010 | Commission |

Appendix 5

www.sundhed.dk

At this point of time the Public Health Portal is the main access point to the primary Health Portal of the Danish health authorities, and enables communication and services between health professionals and citizens. The portal also provides facilities for citizens to book appointments with general practitioners, conduct e-mail consultations with their general practitioners and renew their prescriptions online. The portal provides the following opportunities.

1. Access to patient data in the laboratory systems

The aim of the supporting access to laboratory data is to give healthcare professionals Internet access to patient data stored in another county, hospital or laboratory database. This is usually relevant in situations where the health professional has to treat a patient without having any knowledge of the patient's data, for example in the case of emergency hospital admissions or when treated by a specialist.

2. Access to data local electronic patient records

The Portal introduces web access to data stored in local electronic patient records. The purpose is to increase the accessibility to patient data and to support the clinical decision-making process. Access is granted to doctors and nurses after authentication via a national digital certificate.

3. Appointment booking

By accessing the Portal the patient fills in a form requesting a time for an appointment with the general practitioner (GP). Patients are identified by a personal user-ID and a password distributed by the GP. The request is sent via the Health Data Network to the GP and integrated directly in the GP's appointment calendar. The GP may then choose to either accept or refuse the request. In both cases, an email is sent to the patient's secure mailbox on the GP's website.

4. Prescription renewal for citizens or homecare

Chronic patients may renew their prescriptions regularly, and in many cases there is no need for a visit to the GP's surgery. The prescription service functions in much the same way as the booking of an appointment. However, in this case the patient fills in a form on the webpage and is asked to provide information about the medication s/he wants to have renewed. When the GP has approved the renewal, the prescription is sent electronically to the pharmacy requested by the patient. The patient is then notified by email.

5. Email consultation

The technical solution for the email consultation is the same as the other two services. With the email consultation, the patient can put questions to the GP and ask him or her for advice. Emailing has obvious advantages. It is possible for a patient to send a question immediately when thinking of it, and hopefully s/he will get a fairly quick response. The patients also get an opportunity to ask questions that they might not want to ask face to face.

6. ePrescriptions

Moving away from paper-based prescriptions from the GP, 81% of prescriptions today are sent electronically directly to the pharmacy. The solution is based on the full integration of electronic communications with the GP's electronic healthcare record and the pharmacy systems. The electronic transaction has many advantages. Studies show that handwritten prescriptions cause more work for both the pharmacy and the GP. In addition to being time-consuming, illegible handwriting can cause medication errors. Furthermore, through the electronic administration of prescriptions, the patient does not have to wait for the medication to be administered. Upon entry into the pharmacy, the medication has already been prepared. The patient can go back to work or back to bed much more quickly.

Appendix 6

MyHeart

The MyHeart consortium involves 33 partners from 10 different countries. It is a balanced multidisciplinary consortium of industry (including Small and Medium Enterprises (SMEs)), research institutes, academia and medical hospitals. Prominent industrial partners are Philips, with its medical and technological expertise, Nokia as a leading mobile device manufacturer, Vodafone (Foundation) as a leading service provider, and Medtronic, a world-leader in cardiac technology.

The MyHeart approach is application-centred. Within MyHeart, the CVD application field has been clustered into five major areas, each area representing a prominent risk factor for developing CVD

1. CardioActive: Reduce inactivity
2. CardioSleep: Improve sleep quality
3. CardioRelax: Reduce stress
4. CardioBalance: Reduce overweight
5. CardioSafe: Reduce morbidity by early diagnosis

MyHeart is composed of 16 autonomous application projects called concepts. These concepts are CVD applications tailored to a specific user group or customer segment. The user base includes people who want to stay healthy, people with a recognised risk for developing CVD, chronically ill people and people who have suffered a cardiac event. Examples are Stroke prevention, Myocardial Infarction prevention, Obesity management or Outdoor rehabilitation. Each concept team comprises a clinical partner, to guarantee medical excellence.

Each concept has answered five questions:

- What is the application/value proposition?
- Who are the customers and how to address them?
- How to do it technically?
- Why to believe in the concept (from medical, technical and economical points of view)?
- Where is the business?

Expected end results

The MyHeart project is structured in three phases. Following the concept definition and testing in phase I, the most successful concepts will be selected and combined into 3-5 product-concepts. In the second phase, the selected product-concepts will be implemented and tested in clinical environments to demonstrate their effectiveness and feasibility in long-term test beds.

In phase III, the product-concepts will be validated in extensive test-beds and trials for long-term follow-up. Success will be measured in terms of either the predictive value of the acquired data or the reduction in the number of acute events. Benchmarks will also include parameters like the increase in physical activity and the reduction of hospitalisation days for acute events.

In addition, the cost benefits for the stakeholders in the healthcare delivery system will be assessed. The final outcome is expected to include documented test-beds showing the effectiveness and efficiency of the MyHeart approach, as well as the design of business propositions for the exploitation of the results. It is also intended to establish this healthcare delivery process into the medical guidelines for treatment, thus ensuring Europe-wide access to the outcome of the project. Furthermore, B2C (business to consumer) approaches will be evaluated to ensure that anyone can access the solution before general reimbursement can be achieved with the national healthcare systems.