

e-Health for patient empowerment
in Europe

*e-Salud para la potenciación
de los pacientes en Europa*

José Luis Monteagudo Peña y Oscar Moreno Gil

INFORMES, ESTUDIOS E INVESTIGACIÓN 2007

MINISTERIO DE SANIDAD Y CONSUMO

INSTITUTO DE SALUD CARLOS III

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Information Society
Technologies

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Este trabajo se ha realizado dentro de las actividades del Proyecto eHealth ERA y su resultado incluye las contribuciones de los miembros del Consorcio a través de las múltiples discusiones e intercambio de ideas que se han mantenido. En especial se deben reseñar las revisiones críticas de Dianne Whitehouse y sus recomendaciones, así como los comentarios y sugerencias sobre los contenidos de Stefan Lilischkis.

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Prólogo

El contenido de esta monografía es el resultado de parte de los trabajos realizados dentro del proyecto de investigación eHealth ERA financiado por el Programa de Tecnologías de la Sociedad de la Información para la Salud del 6.º Programa Marco de la Unión Europea.

eHealthERA es una Acción de Soporte enfocada a facilitar la realización de los objetivos del Plan de Acción para e-Salud acordado por la Comisión en colaboración con los Estados Miembros con el fin de dar cumplimiento a la estrategia de Lisboa sobre e-Europa.

Siguiendo las directrices del Grupo Asesor y de la Comisión, eHealthERA ha realizado dos estudios en profundidad sobre grandes grupos prioritarios de aplicaciones de eSalud que han sido «El Resumen de Historia Clínica» coordinado por el Prof. Rossi-Mori del CNR de Italia y el que aquí se presenta sobre «Potenciación de los pacientes» realizado desde la Unidad de Investigación en Telemedicina y e-Salud del Instituto de Salud Carlos III.

La potenciación de los pacientes es una idea que ha tomado un protagonismo creciente en los discursos de política sanitaria como uno de los elementos de sustento filosófico de las propuestas de transformación de los sistemas sanitarios de los países avanzados.

Esta situación ha estado acompañada por el desarrollo de la Sociedad de la Información y la difusión del acceso a Internet de la población en general. Desde la introducción de las primeras aplicaciones de Internet para la Salud se ha podido apreciar su potencial revolucionario para hacer cambiar el papel de los usuarios en su relación tradicional con los médicos y en la gestión de su propia salud en general.

A lo largo de los dos últimos siglos el desarrollo científico y tecnológico ha facilitado herramientas de soporte a la actividad de los médicos con tecnologías que permiten la captación de imágenes diagnósticas, señales vitales, parámetros bioquímicos y otros datos que facilitan el diagnóstico así como instrumental quirúrgico y soportes terapéuticos avanzados. Más recientemente las tecnologías de la información y las comunicaciones han propiciado soportes de e-Salud para la gestión de las organizaciones y las empresas sanitarias. El cambio trascendental que está sucediendo con el desarrollo generalizado de la Sociedad de la Información es que las nuevas tecnologías están facilitando a los ciudadanos medios para tener acceso a la informa-

ción y al conocimiento para el entendimiento y la toma de decisiones sobre su propia salud.

Además ha hecho posible nuevas formas de conectividad entre los usuarios y los proveedores de servicios así como entre los propios pacientes constituyendo asociaciones virtuales en las que los usuarios se constituyen a su vez en proveedores de información.

Las nuevas tecnologías abren la oportunidad al desarrollo de soportes para el mantenimiento de conductas saludables así como la educación en salud y el soporte de diferentes niveles de autogestión de dolencias crónicas o por ejemplo la disponibilidad de sistemas de Historia Clínica Personal controlados por el propio paciente. Las aplicaciones de las TIC para la potenciación de los pacientes comprende una gran variedad de posibilidades de e-Salud mucho más allá de la utilización de paginas web u otros servicios básicos de Internet.

En esta monografía se revisa el estado de situación de las aplicaciones de e-Salud que sirven para potenciar el papel de los pacientes en el contexto de la atención sanitaria.

El estudio se ha basado en la recolección de aplicaciones prácticas realizadas en Europa. Una de las primeras tareas abordadas ha sido la de establecer una taxonomía de clasificación que permitiera un abordaje sistemático del conjunto de aplicaciones de e-Salud para potenciación de los pacientes.

La experiencia acumulada ha permitido realizar un primer análisis del estado de situación y de las perspectivas de evolución así como de las oportunidades de cooperación para su desarrollo en Europa. Teniendo en cuenta el gran dinamismo del sector, posiblemente en el momento de llegar esta obra al lector se hayan producido nuevas iniciativas relevantes y quizá algunas experiencias se hayan abandonado o modificado sustancialmente. Por la propia naturaleza de la materia objeto de estudio, la obra no pretende ser cerrada en si misma sino servir de base a la discusión y creación de pensamiento crítico sobre el papel de las TIC en la salud del futuro y en particular en relación con la potenciación de los pacientes en el marco general del despliegue de la e-Salud de acuerdo con la estrategia i2010 en Europa.

Los autores

José Luis MONTEAGUDO y Oscar MORENO

Madrid, julio 2007

Prologue

The content of this monograph is the result of tasks performed in the context of the eHealthERA project funded under the EC Information Technologies for Health activities of the sixth Framework Program of the European Union.

eHealthERA is a Support Action focused on enabling the accomplishment of the objectives of the eHealth Action Plan accorded by the European Commission in collaboration with the Member States for the fulfillment of the Lisbon strategy on eEurope. Following the guidelines of the Coordination Committee and the Commission, eHealthERA has performed two major studies on two big priority clusters of eHealth applications, namely «Patient Summaries» coordinated by Prof. Rossi-Mori from the CNR in Italy, and the herewith presented on «Patient Empowerment» performed by the eHealth and Telemedicine Research Unit of the «Istituto de Salud Carlos III».

Patient empowerment is an idea increasingly present in the health policy discourses as a philosophic support for the transformation of the health systems in advanced countries. This situation has been accompanied by the development of the Information Society and the generalized diffusion of the access to Internet by the general population. From the very beginning of first Internet applications for Health, it was recognized its revolutionary potential to change the role of the users concerning traditional patient-physician relationship and for the management of his own health in general.

Along the last two centuries the scientific and technological development has facilitated tools for the support of the physicians activity involving technologies that allowed the capture of diagnostic images, vital signals, biochemical parameters and other data for enabling diagnosis, as well as surgical equipment and other advanced therapeutic means. More recently, the information and communication technologies have made possible eHealth supports for the management of the healthcare organizations. A major change is being produced now by the generalization of the Information Society that is providing means to citizens to have access to information and knowledge for the understanding and decision taken on their own health. Furthermore, ICT are making possible new ways of communication between users and service providers as well as among patients f.e. to form virtual associations where the patients become information providers too.

New technologies open the opportunity to develop new supports to maintain healthy behaviors, patient health education and the support of different levels of self-management for chronic diseases or the availability of Personal Health Records controlled by the own patient.

The ICT applications for patient empowerment include a great variety of eHealth possibilities much further than using web pages or other Internet common services.

This monograph reviews the state of eHealth applications serving to enhance the role of the patients in the healthcare context. The study has been based on a quite broad collection of practical implementations across Europe. One of the first tasks has been to build up a taxonomy allowing a systematic analysis of the cluster of eHealth applications for patient empowerment.

The cumulated experience has allowed to produce a first analysis of the situation state and the perspectives of evolution as well as the opportunities for European cooperation in this field. Taking into consideration the sector dynamics, probably when this document should arrive to the readers, new relevant initiatives might have been produced and some registered experiences should have been abandoned or deeply modified. By the own nature of the matter object of study, the document do not pretend to be self closed but to serve as a base for further discussion and for the creation of critical thinking on the role of the ICT in the future healthcare, particularly regarding patient empowerment in the general framework of the eHealth deployment following the i2010 strategy in Europe.

The authors

José Luis MONTEAGUDO and Oscar MORENO
Madrid, July 2007

Executive Summary

This study covers the eHealth based systems and tools serving for the empowerment of health consumers: citizens, patients and their families and caregivers. It refers to any ICT based system, not only using Internet, that enable citizens having more choice and control over their own healthcare. It includes a wide range of eHealth applications from quite simple web sites until complex collaborative systems to support ubiquitous personal care.

To deal with the complexity of it, a practical classification scheme has been designed after the analysis of a representative sample of eHealth patient empowerment applications across EU countries. This taxonomy uses a two-step classification schema. The first grouping level includes five basic sets (voice, data, health ICT and personal care systems). The second level refines the classification for each of these sets.

Patient empowerment is one central element in the EU health strategy. National Health Authorities, EU Bodies, European Council and WHO-Euro are supporting the patient empowering idea.

European experience on eHealth Patient Empowerment have been oriented to: a) providing people access to trusted information and advice; b) supporting patient education for health literacy; c) facilitating the process of accessing and managing own health data (ePHR); d) increasing patient security and convenience (eAppointment, ePrescribing); e) facilitating on-line health behavioral modification (self-care), and d) supporting new models for chronic care (eChronic Care)

The EC have supported several initiatives addressing quality of information at web sites, the launch of the EU Health portal, funding projects by the fifth and sixth FPs (IST Programs) as well as through eTen and the Health Program (DG SANCO).

eHealth strategies of national/regional health systems are explicitly or implicitly using «patient empowerment» as a guiding principle. However, not all eHealth applications, even many of those that claim these features, are actually supporting them.

The most relevant sources of health information for European citizens are «official» portal sites supported by the government directly or by health care agencies. The aim is to provide information and advice about health, illness and health services, to enable patients to make decisions about their healthcare and that of their families. These portals are working coordinated with other information channels like telephone (call centers) and digital TV channels.

Electronic Personal Health Records (ePHR) implementation is still in its early stages in European countries. Actually, ePHR systems are provided by a number of entities ranging from public healthcare services to private health insurance groups. A few commercial offerings exist allowing patients to create their own ePHRs.

Health authorities in European countries are much interested on the implementation of new chronic care models, which is being accompanied by the demand of appropriate ICT tools to support it. Most of the implemented experiences correspond to the «disease management» model.

The diffusion of eHealth-related patient empowerment tools is favored by the general actions promoting eHealth and Information Society (technology push), but in addition from specific consumer demands as well from benefits perceived by physicians, healthcare organizations and governments (market pull). Simultaneously there are also resistances originated in healthcare organizations, professionals and consumers.

A major concern is the gap between high-level declarations and the practical relative low pace of adoption for eHealth tools in daily practice.

The current trends show opportunities for RTD and innovation to reinforce eHealth markets with new products and solutions addressing European society demand. While there is diversity across European countries, there are common themes and opportunities for cooperation, just as there are common challenges.

Following the «ACM» model, the propensity of patients to adopt eServices is a function of three main factors: Access, Competence and Motivation. To improve *accessibility* it is proposed to emphasize the use of mobile technologies and services according with the fact that almost all population use mobile terminals. Future developments can make value on ambient intelligence (AmI) for improving accessibility to information and communication, aligning efforts with the RTD priorities at 7FP. Other strategic line for action is to work on the accessibility, particularly thinking on elderly and handicapped people in line with e-Inclusion EU policy.

Patient education appears as a key strategic action promoting patient *competence*. It should benefit on research efforts on eHealth for «personalized patient education», including the use of ePHR as the base for it.

People will be more motivated to use eHealth systems that produce visible benefits solving real actual needs. In line with this it seems appropriate to work on eHealth for chronic and elderly care.

New technologies will address many of the technical issues to implement patient empowerment applications, but there are some aspects that lie beyond the technology which are part of the new social and relational context of the emerging eSociety. A major challenge is to integrate

eHealth patient empowering tools and systems into standard health care processes, organizational structures and technological infrastructures, making it interoperable with healthcare information systems. In this context, professionals' acceptance and their active involvement must be carefully considered.

1. Introduction to the document

1.1. General

This study deals with the eHealth based systems and tools serving for the empowerment of health consumers: citizens, patients and their families and caregivers.

Patient empowerment refers to a philosophy and eHealth represent the tools that make possible its practical implementation.

There is a wide and growing literature addressing Patient Empowering in health management domain. However, the studies concerning the use of IT tools for patient empowering are not so common. Traditionally, studies have been focused on the Internet supported applications but now the scope of interest and the range of implemented applications are becoming wider.

Information and education of citizens are basic elements for patient empowerment and they constituted the most popular area of eHealth applications. Nevertheless, interest is growing about areas such as enhancing the communication between citizens/health organizations and between patients/health professionals. Also, works are being directed to the development of tools to support sharing decisions aids.

Furthermore, a growing line of development is becoming linked to the patient engagement, and self-care in particular, regarding the new approaches for chronic illness care. It is envisaged that most cases of chronic illness will be self-managed by the individual or her/his family. In this context eHealth becomes a masterpiece for practical policy implementation.

1.2. Background

Rationale for this Topic Cluster choice was established after eHealthERA Project discussions at Consortium meetings. Reference framework and key elements are described at the document: «Revised background document for Topic Cluster 1, with details of the potential subclusters». January 15, 2006. A.Rossi Mori and J.L. Monteagudo.

Basis for this report were stated in document «Priority Cluster 2» of May 1, 2006 (JL Monteagudo).

1.3. Object of the document

The results of the works performed for the study on the cluster of eHealth applications on «Patient Empowerment» is intended to offer a base for further analysis and open new views on opportunities for co-operation on eHealth in the EU.

Analysis consists on the

- Definition of Topic Cluster scope and content.
- Mapping the overall Topic Cluster activity across EU
- Identification of major activity lines, key issues and trends
- Identification of potentialities and areas for recommended action

The study is expected to serve for a better knowledge of the state of situation and the main trends on eHealth applications for patient empowerment in Europe aiming to identify basis for research policies in this domain following i2010 strategy.

1.4. Structure and content

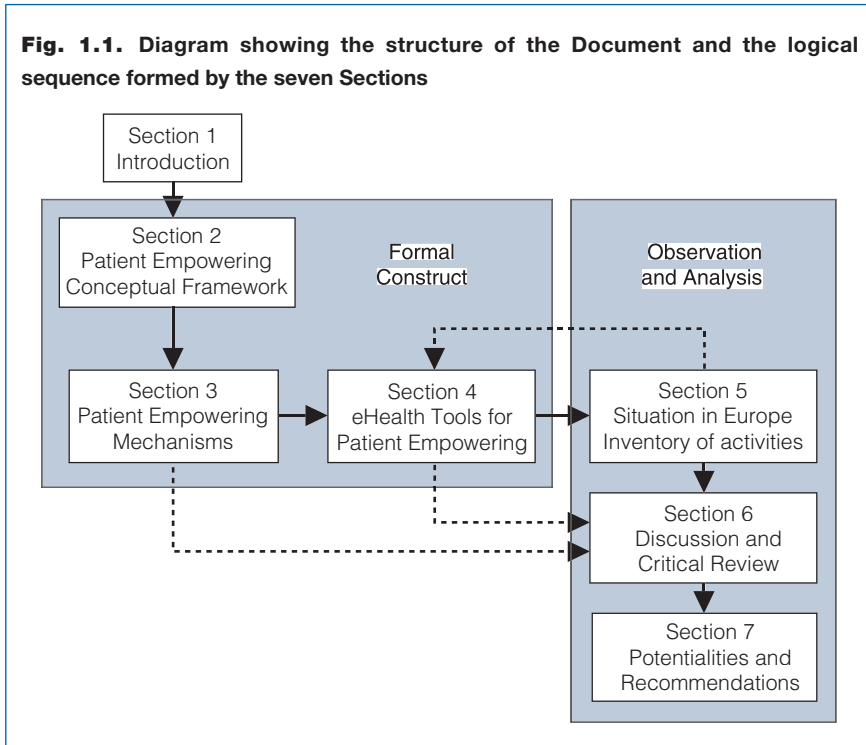
The structure of the Report is shown graphically in Fig 1.1. Section 2 is devoted to de foundations of Patient Empowerment presenting basic definitions, concepts and key issues. It is completed with a description of the main mechanisms in use for implementing Patient Empowerment in practice along Section 3.

These reference materials are followed by Section 4 which is centered on the analysis of eHealth applications concerning Patient Empowerment implementation. These eHealth tools are grouped in representative generic classes forming a basic taxonomy to facilitate the description of the situation and its analysis.

The overall situation in Europe is mapped at Section 5 including a comprehensive list of representative projects leaded under the initiative of the CEC and Member States. This inventory serves to obtain a general picture of the eHealth for patient empowering situation in Europe regarding practical implementations for routine operation, further than pilots and research projects.

Based on collected data, the situation on eHealth and Patient Empowerment in Europe is critically reviewed and discussed in Section 6. Finally Section 7 presents future prospects and recommendations regarding ERA objectives, describing opportunities and obstacles for EU cooperation.

Fig. 1.1. Diagram showing the structure of the Document and the logical sequence formed by the seven Sections



2. Introduction to Patient Empowerment

2.1. General

The term «patient empowerment» describes a situation that citizens are encouraged to take an active part in their own health management. Patient empowerment is considered as a philosophy of health care that proceeds from the perspective that optimal outcomes of health care interventions are achieved when patients become active participants in the health care process. It makes emphasis in the importance of individual involvement in health decision making.

Patient empowerment is a concept that is growing in popularity and application. Managerial implications and directions for practical deployment of «patient empowerment» idea have been object of many discussions by experts on healthcare services research during last 30 years. A central matter is the model for incorporating patient empowerment practically into real life healthcare delivery processes as a routine. Personal empowerment has been considered as a powerful instrument for healthcare change. For some experts, redefinition of the traditional patient is probably the biggest driver of change in healthcare.

The patient empowerment discourse is based on a number of assumptions including the idea that patients want to be in control of their healthcare, and that such control will yield benefits for patients. In addition, it presumes that healthcare providers support patient control of their healthcare. Furthermore, it is widely assumed that information empowers patients, and that informed and empowered patients take better care of their health. However, these assumptions require critical examination in the context of practical situations to work on real bases and to avoid pitfalls.

2.2. Patient Empowerment. Conceptual framework

The term empowerment has a wide use in literature of many disciplines connected with healthcare. There are a variety of definitions depending on

the specific field of application and the origin of the school of experts. Skelton (1) pointed the origins of the expression of «Patient Empowerment» in community development work. Definitions from Zimmerman (2) and Gibson (3) are two of the most referred in the literature. Authors, such as Ellis-Stoll and Popkess-Vawter have discussed on the concepts around the empowerment process (4). Spite differences in definitions of «patient empowerment», the central idea is that empowered patients attempt to take charge of their own health and their interactions with health care professionals and healthcare organizations. Patient empowerment involves complex questions concerning the distribution of power between those who use and those who provide health services.

Empowerment can occur at different levels and patients have different ideas about what it means to take charge and to be empowered. Some patients simply want to be given information about their conditions whilst others want to have full control over all medical decision-making. In connection with it are the implications of the use of terms such as patient, client, or consumer. As discussed later, «patient empowerment» is concerned with «inclusion» and «vulnerable populations».

2.3. The driving context

The patient empowerment concept and its practical implementations have been developed historically in a context of co-existing trends which acted as synergistic factors for overall healthcare change. All them can be considered as driving actors of a general movement that, with different tints and intensity grades, has been present on the healthcare change policies of EU Member States.

According with Harris and Veinot (5) major identified contextual associated trends are: self-help and mutual aid; healthcare consumerism; rise of alternative medicine; patients organizations and activism; constrain in health care spending, and the impact of information society.

(1) Skelton R. Nursing and empowerment: concepts and strategies. *J Adv Nurs*. 1994 Mar;19(3):415-23.

(2) Gibson CH. A concept analysis of empowerment. *J Adv Nurs* 1991;16(3):354-61.

(3) Ellis-Stoll CC, Popkess-Vawter S. A concept analysis on the process of empowerment. *ANS Adv Nurs Sci*. 1998 Dec;21(2):62-8.

(4) Zimmerman MA, Rappaport J. Citizen participation, perceived control, and psychological empowerment. *Am J Community Psychol* 1988;16(5):725-50.

(5) Harris R and T.Veinot. «The empowerment model and using e-health to distribute

The principles of self-help and mutual aid have been inspiring the philosophic bases of patient empowerment. A notable growth of self-help groups can be observed in Western Countries along the last three decades in a way that can be considered quite close to a social movement.

Healthcare consumerism has been other relevant trend that has accompanied the maturation of patient empowerment idea. In market rhetoric, patients are considered to be consumers of health care. While the term patient is associated with passivity, the term consumer is intended to evoke notions of rights, power and empowerment. There is an overall trend of patients to become consumers instead of simply passive user of services (6), although it is not so marked in EU countries as in US.

Consumer power may take two forms: a) the ability to make choices and b) legal rights. Regarding the first aspect, consumerism is concerned with the right of people to choose the healthcare goods, products and services they purchase. In this line, it has been observed that consumers want better quality, highly speed, more choice, appropriateness of care, and affordability of healthcare services. It has been argued that this should lead healthcare market to move to more personalized services and consumer choice.

On the aspect of legal rights, consumerism has been concerned historically with issues such as patient's rights to privacy and confidentiality, informed consent to medical treatment and disclosure of information. It has lead to widespread introduction of Patient's Bill of Rights, legal treatment for informed consent, introduction of patients representatives in hospitals, increase in malpractice litigation, and other legal aspects.

Consumerism has played a relevant role in health care policies in some EU member states, such as UK and Germany.

The growth of Alternative Medicine has been also evident in last years. Studies on this trend shown its acceptance by people is based on their confidence that Alternative Medicine can contribute to remedy health problems used jointly with traditional medicine better than any of them alone. Also, people perceive alternative practitioners devote time to them and attention listening. It has been noted that the use of alternative medicine can also facilitate people with life-threatening or chronic illnesses certain sense of control over their health and healthcare (7).

The rise of patient empowerment popularity can be connected with the growth of patient organizations and activism. Several aspects of the

(6) Hamilton PA. Health care consumerism. St. Louis: C.V. Mosby Co., 1982.

(7) Foote-Ardah CE. The meaning of complementary and alternative medicine practices among people with HIV in the United States: strategies for managing everyday life. *Social Health & Illness* 2003;25(5):481-500.

patient organizations activities are particularly relevant to the practical implementation of patient empowerment approach, including the involvement of patients or their families in the provision of services, as well as the role of patient organizations influencing healthcare programmes and health services planning. Patients' organizations have become relevant players in the political arena in some countries (8).

Patient empowerment has been considered as a potential tool to implement cost containment policies based on the shift in the responsibility for much healthcare to the patient (9) (10). Examples of this include the encouragement of chronically ill patients to «self-manage» their illness and increased outpatient medication therapy for even the most serious conditions. In fact, quite often, patients are acting as their own «care integrator» because of the variety and fragmentation of care services used (11). In this situation, patient empowerment seems to be used to serve the interests of healthcare institutions and administrations rather than directly serve those of the patients.

Many «Patient Empowering» literature assumes a deep connection of its development with Internet deployment. Certainly, Internet represents a very powerful tool for implementing the idea of patient empowerment. A broader vision on eHealth capabilities for patient empowerment has been formed further than the simple provision of static information at Health portals and basic e-mail services. In one way or in another, most policy discourses on eHealth infrastructures are addressing their capacity to act as instruments for producing patient empowering. However, most practical implementations are aiming first to empower organizations.

(8) Jones K, Baggott R, Allsop J. Influencing the national policy process: the role of health consumer groups. *Health Expect* 2004;7(1):18-28.

(9) Neuhauser D. The coming third health care revolution: personal empowerment. *Qual Manag Health Care*. 2003 Jul-Sep;12(3):171-84

(10) Ramsaroop P & Ball J. The «Bank of Health» A Model for More Useful Patient Health Records. *MD Computing*. Vol. 17, No. 4, July/August 2000:45-48.

(11) Chewning B, Sleath B. Medication decision-making and management: a client-centered model. *Social Science & Medicine* 1996;42(3):389-98.

2.4. Patient empowerment at the European health space

2.4.1. Patient empowerment and EU Health Strategy

Patient empowerment is one central element in the EU health strategy. It was clearly declared by David BYRNE, former European Commissioner for Health and Consumer Protection, in the document: «Enabling Good Health for all. A reflection process for a new EU Health Strategy» (12) of 15 July 2004.

The current EU «Programme of Community action in the field of public health (2003-2008)» (13) includes actions on the quality of health information at web sites and the launching of the Health Portal to serve European citizens.

The proposal of the next «Programme for Community Action in the field of Health 2007-2013» (14) relays on three main objectives: 1) Improve citizens' health security; 2) Promote health for prosperity and solidarity, and 3) Generate and Disseminate Health Knowledge

The quality of information at web sites and the Health Portal are maintained in the objectives of the new Program.

It can be argued that these actions are supporting patient empowerment but they are relatively modest and limited in scope. It is interesting to note that the term «patient empowerment» do not appears along all the draft text of the current EU Health Program.

2.4.2. Council of Europe activity

As regards the Council of Europe, one must recall in particular the 1997 Convention on Human Rights and Biomedicine, as well as Recommendation Rec(2000)5, for the development of institutions for citizen and patient participation in the decision-making process affecting health care. All these documents consider citizens' health care rights to derive from fundamental

(12) http://europa.eu.int/comm/health/ph_overview/strategy/health_strategy_en.htm

(13) http://ec.europa.eu/health/ph_programme/programme_en.htm

(14) http://ec.europa.eu/health/ph_overview/pgm2007_2013_en.htm

rights, and the governments are requested to associate more closely with patients on decisions regarding health policies.

The Recommendation Rec(2004)17 of the Committee of Ministers to Member States on the impact of information technologies on health care - the patient and Internet (Adopted by the Committee of Ministers on 15 December 2004 at the 909th meeting of the Ministers' Deputies) includes guiding principles.

2.4.3. The position of WHO-Europe

Regarding WHO-Europe, the activity on this matter can be traced historically to the following documents:

- The Declaration on the Promotion of Patients' Rights in Europe, endorsed in Amsterdam in 1994;
- The Ljubljana Charter on Reforming Health Care, endorsed in 1996;
- The Jakarta Declaration on Health Promotion into the 21st Century, endorsed in 1997.

WHO-Europe makes explicit reference at his official web page to the declaration on «Patient Empowerment» agreed by The European Forum of Medical Associations at the meeting held in Dubrovnik, Croatia on 16-17 April 2004 (15).

2.4.4. Contribution from the Active Citizenship Network

The «EUROPEAN CHARTER OF PATIENTS' RIGHTS» (Cittadinanzattiva-Active Citizenship Network) issued a basic document resulting from the meeting held at Rome on November 2002 aiming to influence on the European Constitution content. This document includes key references to the rights to *Information, Consent, Free Choice, Privacy and Confidentiality*.

2.5. Patient empowerment in the EU Member States

Patient empowerment is one element of reference in the health care policies of EU Member States. Despite their differences, national health systems in European Union countries place the same rights of patients, consumers, users, family members, weak populations and general people at risk. However, apart from solemn declarations on the «European Social Model» (the right to universal access to health care), several constraints call the reality of this right into question. Examples of policy declarations can be found at UK Department of Health (2004) (16), or more recently those performed by Ulla Schmid, German Federal Minister of Health (2006) (17) declaring that «*Informed patients who manage their own health are indispensable partners in a modern health care system*».

Each of the national health systems of the EU countries shows quite different realities with respect to patients' rights. Some systems may have patients' rights charters, specific laws, administrative regulations, charters of services, bodies such as ombudspersons, procedures like alternative dispute resolution, etc. Others may have none of these.

European countries are at different stages of implementing patient empowerment policies in their healthcare systems. Despite the rhetoric, the real implementation level and approaches varies greatly depending on the country. Some public systems are seeking to enhance patient choice (Denmark, Norway, Spain, UK). The main purpose is to enhance quality improving parameters such as waiting times.

Having more choice and control over citizens' own health and care is claimed to be at the very heart of the Government's vision for the National Health Service (NHS) in England. In Denmark «Free choice»/«extended choice» of hospitals was introduced on the public agenda in the early 1990s. Similarly, in Norway free choice of hospital was implemented in the whole country on January, 2001. In addition to new parts in the Act also information activities has increased, such as national quality indicators and a public web page to make the choice easier for the patient.

(16) UK Department of Health (2004). Improving Chronic Disease Management. www.dh.gov.uk

(17) Ulla Schmidt, German Federal Minister of Health, «Health Policy and Health Economics in Germany». Speech at the conference, «The American Model and Europe: Past - Present - Future,» organized by the Friedrich Ebert Foundation, Washington, DC. January 27, 2006. http://www.germany.info/relaunch/politics/speeches/012706_1.html

In other EU countries, social insurance systems are seeking to circumscribe patient choice (France, Germany). The purpose is to encourage use of «preferred providers» to improve quality and moderate cost.

The French Parliament adopted a «Patients Rights and Quality of the Health Care System» law in 2002 (18). Under this law, patients are responsible for decisions regarding their health status (having been provided with extensive medical information leading to informed and free consent) and thus become partners with health professionals. The law also recommends that representatives of patient groups be included on advisory boards whose decisions affect patients.

Regarding former East Countries, the issues concerning patients' empowerment and citizens' participation are not reflected in the World Health Organization's «health in transition» reports for these countries. In the reports for nine new candidates for the European Union, the word empowerment doesn't appear at all. Patients' rights are absent from three reports and mentioned only as short references to existing laws in five, whereas citizens' participation appears only in the report on Slovenia.

2.6. Drivers for patient empowerment in EU countries

Patient empowerment philosophy is under the effect of different drivers and resistances that vary at each European country. Recent studies (19) have identified a number of relevant driving forces, as follows:

- The Healthcare System
- Powerful Advocacy Groups
- The strength of media influence in healthcare issue
- The industry (Direct-to-consumer marketing)
- Use of Internet

The referred study was oriented to pharmaceutical market assessment, but it offers an overall vision of the different profiles at US, Japan and several

(18) «Patients Rights and Quality of the Health Care System», Republic of France, Law No. 2002-303, 4 March 2002. <http://www.legifrance.gouv.fr/WAspad/UnTexteDeJorf?numjo=mexx0100092l#>.

(19) Natasha Jenkins. *Patient Power: the shift towards more informed, more powerful consumers of drugs* Business Insights, London, UK.

European countries. The Table below displays graphically the relative role of each of these factors in each country.

The influence of all the driver factors are rated at maximum value for US, perhaps because it has been used (conscientiously or unconscientiously) as the reference health market for the referred study.

It must be noted the action of direct-to-consumer marketing in the US is different compared to Europe because of the different legal context. Regulations affecting direct-to-consumer marketing in Europe are much more strict than in US. In 2004, pharmaceutical companies spent more than \$4 billion in advertising to promote prescription drugs in US (20). The direct action on consumers goes beyond the marketing of drugs. During the past five years, the marketing of health care products has begun to bypass the health care professional and aim directly at the consumer. Advertisements for medical products or procedures are becoming common at newspapers, magazines, the television, or the radio. This trend is noted also in Europe but at much less intensity.

Regarding overall effect, it can be observed UK (high) just behind US(very high), followed by France, Italy and Germany (medium). Spain and Japan present lowest scores (low)

As we can see, the situation at Japan is more similar to the European countries (unless on the absence of advocacy groups influence) than to the US one.

The effects of the use of Internet is rated higher in UK than in any of the other EU countries, probably explained by the succesful implementation of the «NHS-on line».

(20) M. Cross. «How Much Trouble Does Health Care Marketing Cause?» MANAGED

Table 2.1. Level of influence on patient power by different drivers in different EU countries, US and Japan

Driver	France	Germany	Italy	Spain	UK	Japan	US
The Healthcare System	****	***	***	***	***	***	*****
Powerful Advocacy Groups	***	**	***	***	****	*	*****
The strength of media influence in healthcare issues	***	***	***	**	****	**	*****
Use of Internet	**	***	**	**	****	***	*****
Direct-to-consumer marketing	*	*	*	*	*	*	*****
Overall effect	***	***	***	**	****	**	*****

Key: very low *; low **; medium ***; high ****; very high *****

Adapted from: Natasha Jenkins *Patient Power: the shift towards more informed, more powerful consumers of drugs* Business Insights, London, UK.

3. Mechanisms for patient empowerment implementation

3.1. General

Patient empowerment in healthcare systems have adopted several forms and used different instruments for implementation across healthcare systems. There is no a clear classification of models of implementation and quite often several mixed mechanisms are involved.

After the analysis of the literature and the review of the known practical experiences, we have adopted an instrumental approach for the classification of the mechanisms for patient empowering. It is based on key activities, as follows

- Consumer **Communication** with health agents and carers
- Consumer Health **Information** access
- Consumer Health **Education** process
- Consumer **Decision making** aids
- Consumer **Self-care** support
- **Chronic Care** integrated services support

The above identified mechanisms are discussed with more detail in the following paragraphs

3.2. Consumer Communication

One first, basic means for patient empowerment consists in facilitating consumer communication with the healthcare agents, particularly with physicians. The improvement of patient-physician relationship has been always object of great interest because it is a very sensitive element of the practice of the medicine.

From the invention of the telephone, telecommunication technology has been used for patients to be in contact and communicate with doctors. The advent of the e-mail services by the Internet and the popularization of mobile communications (voice and SMS) has multiplied the expectancies for extent to the healthcare sector what has become so common for communicating people in current life.

3.3. Consumer health information access

It is widely assumed that the access to information is a basic mechanism for patients empowerment. The issue is that consumers, personally, should be able of actively search out proper information to understand their health conditions and their treatments. The challenge is to improve citizen's access to good health information and their capacity to use it effectively. A number of strategies can assist patients in this process. These are linked to the promotion of the motivation and the capacities of the people to access the information, but on the other hand it is required the availability of trusted health information to be accessed (21).

To be useful, consumers must understand and be able to apply properly the accessed health information and knowledge.

There is a great concern on the quality of health information made available through Internet. This is one area widely discussed last years and it is object of mayor interest at EC and Member States.

3.4. Health Education, Consumer Health literacy and Patient Empowerment

Health literacy as a concept is directly linked with patient empowerment. According with the WHO health promotion glossary: *«Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment»* (22).

Health literacy can range from simple functional skills to high level capacities for critical analysis of information and to take decisions. Health literacy is based on improved access to information and knowledge, but also refers to informed consent and the capacity of negotiating skills. It concerns

(21) Funnell et al. Diabetes Educ. 2003;29:454-464.

(22) Nutbeam, D.(1986) «Glosario de Promoción de la Salud». Separata técnica de la revista *Salud entre todos*. Sevilla: Consejería de la Salud (v.o. «Health promotion glossary» *Health Promotion: an international journal*, 1 (1) 113-127) <http://heapro.oxfordjournals.org/cgi/reprint/13/4/349> (01.09.2006)

health care resources utilization and the active participation in health promotion activities (23).

Citizens education also promote knowledge on matters such as: how the health care system functions in a country or at the local site; the advantages and disadvantages of various health insurance/provision options; the availability and purpose of self-help and advocacy groups for particular diseases; the position of carers for seriously disabling conditions; and how political, scientific and bioethical trends will affect persons and his health.

High levels of health literacy facilitate personal benefits, such as healthier lifestyle choices and effective use of the health services. Furthermore, the ability to use information effectively, can lead to social benefits, e.g. by enabling effective community action for health (24). In addition, other studies have highlighted the importance of health literacy in economic terms. In a strategy paper commissioned by the Swiss Federal Office of Public Health (FOPH), the Office for Employment and Socio-Political Studies (BASS) in Bern estimates that insufficient health literacy accounts for around 3% of health spending. The BASS strategy paper concludes that insufficient health literacy has an impact on all of the objectives of the national health insurance scheme.

Poor health literate people are less informed and should suffer poor healthcare access whereas can produce supplementary costs to the healthcare system because of inadequate or inappropriate use of healthcare resources. Poor health literacy is more likely detected among older people, immigrants and those with low incomes. Efforts to improve health literacy should be intensified to these populations along with e-Inclusion actions.

Personalized patient education and the Internet has been analyzed by Dupi (25) addressing highly relevant aspects, such as the issue of online health information quality and the problem of integrating Electronic Patient Record data and Internet health information.

(23) Kickbusch, I. (2001). Health literacy: addressing the health and education divide. *Health Promotion International*, Oxford. Vol. 16, 289 – 297.

(24) Chrismann, S., EuroHealthNet, 2005, Health Literacy and Internet; www.eurohealthnet.org/Eurohealthnet/documents/healthliteracy-final.pdf

(25) Doupi, P. (2005) Personalized Patient Education and the Internet: Linking health information to the Electronic Patient Record. STEPPS in burn care. *STAKES Research Report 152*. 193pp. Finland

3.5. Patient Decision Aids

A key characteristic of patient empowering is the capacity of patients for decision taking about his healthcare options. Patient decision aids or «shared decision making programs» are interventions for preparing patients for decision making about professional care options. They are meant to supplement rather than to replace the counselling provided by health practitioners.

According to the Cochrane Collaboration, decision aids for professional care options are defined as:

«...interventions designed to help people make specific and deliberative choices among options by providing (at the minimum) information on the options and outcomes relevant to the person's health status. Additional strategies may include providing: information on the disease/condition; the probabilities of outcomes tailored to a person's health risk factors; an explicit values clarification exercise; information on others' opinions; and guidance or coaching in the steps of decision making and communicating with others. Decision aids may be administered using various media such as decision boards, interactive videodiscs, personal computers, audiotapes, audio-guided workbooks, pamphlets, and group presentations.»

Excluded from the definition of decision aids are passive informed consent materials, educational interventions that are not geared to a specific decision, or interventions designed to promote compliance with a recommended option rather than a choice based on personal values.

A systematic review of the Inventory of Decision Aids provided by Cochrane (26) reveals that the use of Internet dominates (79%) is the main channel used for communication support.

(26) Cochrane Systematic Review Group. A-Z Inventory of Decision Aids. <http://decisionaid.ohri.ca/AZinvent.php>.

Table 3.1. Type of Materials used for Patient Decision Aids

Support Materials	Relative Percentage
Booklets plus audio records	2%
Booklets plus video records	7%
Only paper (sheets, booklets, working books, etc)	11%
Available from Internet	79%
Available in digital format (programs) or CD-ROM	1%

More frequent strategies used for facilitating the participation in decision taking are of one of the three types: a) information combined with advice; b) advice from the clinician who attends the patient, and c) advice from a trained third part counselor.

The relationship of patients with physicians is a very important factor to consider for patient empowerment. Patient power and the influence of patient in physician-patient relationships are correlated as reported in recent studies (27).

There is not yet good evidence on the best means of sharing information with patients. There is quite few evidence to guide how physicians can most effectively share clinical evidence with patients facing decisions (28) (29).

3.6. Consumer Self-care support

Along the last two decades it has been produced the growth of different groups of organized citizens (patients, consumers, advocacy groups, advice-

(27) Natasha Jenkins *Patient Power: the shift towards more informed, more powerful consumers of drugs* Business Insights, London, UK

(28) Institute of Medicine. Health literacy: a prescription to end confusion. Institute of Medicine, 2004. <http://www.nap.edu/books/0309091179/html/301.html>

(29) Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. *JAMA*. 2004; 291:2359-2366.

givers, self-help groups, voluntary and grassroots organisations, etc.) that have the main role of supporting and empowering individuals. The relevance of the movement can be observed for example by Google searching for «cancer support group» produces 624.000 results.

Consumer communities support self-education and self responsibility, encourage patients' initiative, and provide members with an opportunity to help others (30). Several studies provide evidence on high levels of support in online communities and the capacity of virtual communities as a way suitable for consumer learning (31).

3.7. Empowering patients with chronic illness

Patients with chronic conditions are frequent and long-term users of health services, accounting for a high rate of GP consultations, hospital bed days and emergency admissions. It is now widely recognised that effective management of chronic illness entails an active partnership between healthcare professional and patient, in which education and support for self-care should be a key component.

Patients with long term conditions need personalised care to meet their individual requirements. This mean active partnership between healthcare professional and patient, in which education and support for self-care should be a key component.

Patient engagement, and self-care in particular, have been strongly emphasised in the reform of chronic illness care. The growing burden of chronic and long term conditions has exposed significant limitations in traditional models of care delivery which are reactive, curative and focused on acute, episodic illness. Consequently, there has been a move towards implementing a disease management approach, which seeks to co-ordinate services across the health and social care sectors in order to deliver ongoing care.

A number of studies have looked at various aspects of patient engagement in healthcare, although few have specifically examined

(30) Demiris G. The diffusion of virtual communities in health care: concepts and challenges. *Patient Educ Couns.* 2006 Aug;62(2):178-88. Epub 2006 Jan 6

(31) Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ.* 2004 May 15;328(7449):1166

people's capacity for and attitudes towards self-managing chronic illness. While public opinions vary, there is evidence that some people do want greater involvement in healthcare, including a stronger role in decisions about treatment. For example, surveys of NHS patients in 2004 found that 47% of inpatients, 30% of outpatients, 36% of emergency patients, 32% of primary care patients, 39% of coronary heart disease patients and 59% of mental health patients would have liked more input and choice in decisions about their care (32).

Observed trend show that a significant number of patients should be in favour of more involvement in decisions about their care; better information about health problems and conditions, treatments and lifestyle issues; and greater stimulus for health professionals to support self-care practice. However, while research has investigated public attitudes toward self-care, and many opinions are only based on intuitive reasoning, relatively little is known about the capacity of patients and the public to be successful self-managers of their health and healthcare and about the most appropriate procedures to improve it.

(32) Picker Institute Europe, *Is the NHS Getting Better or Worse? An in-depth look at the views of nearly a million patients between 1998 and 2004* (Oxford: Picker Institute Europe, 2005).

4. eHealth tools for Patient Empowering

4.1. eHealth and patient Empowering

«eHealth can empower patients and improve healthcare». This statement was made by European Commissioner Markos Kyprianou (Health and Consumer Protection), on May 2005, at the eHealth Conference 2005 held in Trömsö, Norway.

Certainly, it is widely recognized the potential of Internet, and ICT technologies in general, to support the implementation of patient empowerment policies. During last years a wide number of eHealth tools and applications have claimed to support patient empowerment. They range from using generic phone, e-mail, or SMS services to dedicated Internet Health Portals and Interactive Web services, as well as healthcare specific applications such as Personal Health Records, e-Prescribing, and Chronic Care Management Systems based on mobile e-care.

However, not all eHealth applications serve patient empowerment. In fact most of them were first designed to support organizations or professionals.

In the following paragraphs we present a characterization of eHealth applications focused on patient empowerment. We propose a classification schema for types of so recognized «eHealth patient empowerment tools». This schema has been produced after the analysis of a broad representative sample of practical eHealth implementations claimed to support patient empowering across Europe. The details of the overall sample are displayed in the next Section 5.

A clustering process has been used to identify representative groups (types) of «practical» implementations. In this Section, these types are described with some detail and are mapped with the patient empowering mechanisms they support.

4.2. Identification and classification of eHealth patient empowerment applications

Patient empowerment means citizens having more choice and control over their own health and care. Consequently, we define «eHealth for patient

empowerment» as *any ICT based system, not only Internet, that serve citizens having more choice and control over their own health and care.*

For the purpose of this report (Cluster 2 Analysis) we only consider applications of «eHealth for patient empowerment» those eHealth systems whose empowering capabilities can be directly traced. We do not include eHealth applications that may have «indirect» empowering effects.

The variety and complexity of patient empowering mechanisms we discussed earlier, jointly with the expanding range of available ICT technologies make quite wide the number and variety of eHealth patient empowerment systems to be analyzed.

A traditional approach to reduce complexity is to produce a classification on different subsets by grouping the analyzed elements according with some relevant criteria to produce some kind of taxonomy.

The only previous intent we know on classifying eHealth patient empowerment applications was produced in the context of the Awards for eHealth2004 (Cork eHealth Conference) (33). Three grouping categories were used as follows,

Category 1: *eHealth information tools and services for consumers* focusing on the electronic provision of health and wellness information to citizens. Examples of such tools included general health portals or intelligent aids to interact with databases searching for tailored information

Category 2: *eHealth management support tools and services for consumers* focusing on applications which allow citizens to interface with health service providers electronically in order to better support their use of health services. Such tools included electronic appointment booking, eligibility assessment, or ePrescriptions;

Category 3: *eHealth homecare and telemedicine tools and services for patients* focusing on applications that allow citizens who are receiving healthcare to be supported in their personal environment, whether fixed or mobile, outside traditional healthcare facilities. Such applications included eHealth tools for the monitoring of conditions and treatments (e.g. pacemaker monitoring, remote ECG); eHealth tools for interactive diagnosis and support of citizens at home (e.g. dermatology, wound management) and eHealth for emergency and risk management (e.g. triage, accident and emergency management).

(33) Wilson, P.; Leitner, C.; Moussalli, A. (2004). Mapping the potential of eHealth. Empowering the citizen through ehealth tools and services. Presented at the eHealth conference, Cork, Ireland, 5-6 May 2004. www.ehma.org/_fileupload/publications/MappingthePotentialofeHealth-FULL.pdf (25.04.2006)

It can be observed, the three proposed categories correspond with the type of actors that consumer communication is facilitated, i.e.:

- Category 1: communication of consumers with machines (web sites at Internet)
- Category 2: communication of consumers with organizations (healthcare organization/service providers), and
- Category 3: communication of patients with healthcare professionals/carers

The above approach using only three categories facilitates a simple classification that was quite useful for the Cork eHealth2004 Awards, but clearly it was broad for the objectives we pretend for Priority Cluster 2 analysis in the eHealth ERA project. For our purposes we desire a better degree of granularity to cope with the rich variety of eHealth applications to analyze.

4.3. Defining a typology for eHealth Patient Empowerment tools

Based on the collected sample of existing eHealth patient empowerment applications in EU Countries (See section 6) we have produced a classification schema based on two steps classification tree. The first step is constituted by 5 big categories (layers) of eHealth applications as represented in Fig. 6.1. following a layers model of growing specialization from applications using basic generic ICT tools (at the bottom) to the most patient specific developments (at the top). These identified big categories are:

L0: Information production. It included tools and supports for information and educational materials in electronic formats. The new technologies have facilitated the transformation of patients into producers of health information not only consumers. Electronic publishing is more timely and dynamic than traditional publishing. Also it is less expensive than paper based publishing.

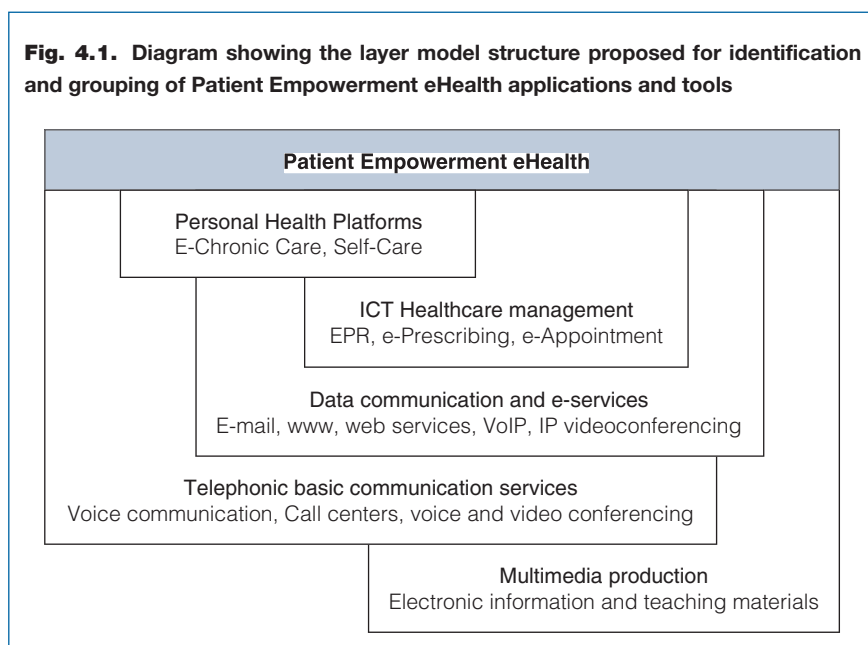
L1: Telephone communication services. It refers to applications and tools supported by generic telephonic services such as call centers, voice mail, audio conferencing, etc. using fixed and mobile telephonic networks

L2: Data communication services (no healthcare specific). This layer includes applications constructed using e-mail, Mobile SMS, web pages and Internet interactive services. These services can be simple passive information

of administrative nature, to complex health interactive services or virtual communities support.

L3: ICT Healthcare management using specific applications and services as for example Electronic Personal Records (EPR), electronic prescription and electronic appointment systems.

L4: Personal Health Platforms to support complex processes of care delivery based on partnership of different actors and the active collaboration of the patient. They are constructed using or interacting with eHealth applications of the above categories. This is the case, i.e. of systems for Self-Care Management and Chronic Care.



This big layers classification reflects the increasing complexity and the level of specialization of the different solutions from bottom to the top. Each level can integrate elements of a layer at a lower level.

It can be observed «Cork» Category 1 can be mapped on Layer 1 and Layer 2 whereas Categories 2 and 3 can be mapped on Layers 3 and 4 respectively.

To increase the level of definition, the classification scheme we propose identifies a second level of types of eHealth applications for each of the «Layers» as described in the Table below.

These «types» have been obtained after sub-clusters identification in the set of analysed cases used for our study (See Section 6). Thus, this classification responds to the observed «population» of eHealth applications for patient empowering across EU countries.

4.4. Overall description

4.4.1. Health portals. Access to Health Information

It is widely recognized that the access to health information by electronic means empowers patients and equalizes the physician-patient relationship because it diminish the knowledge asymmetry that has historically presided that relationship. This access to information is believed to increase the control that patients can made in their healthcare.

The on line resources available in Internet provide consumers with 24 hours access to health information and referral, advice and emotional support in a broad range of topics.

4.4.2. Interactive services for Virtual Communities

A virtual community in health care is a group of people using ICT tools with the purposes of delivering health care and education, and/or providing support, covers a wide range of clinical specialties, technologies and stakeholders. Examples include peer-to-peer networks, virtual health care delivery and research teams. Interactive services like online self-help-groups, chats with experts and forums on special health topics have habilitated the growth of virtual communities and electronic support groups.

4.4.3. Personal Health Records

PHRs are a set of computer- and Internet-based tools that allow people to access and coordinate their health information and make appropriate parts of it available to those who need it.

The introduction of web-based personal health records (PHR) has been considered by some authors to revolutionize communication between patients and healthcare professionals. But the sharing of sensitive electronic health information requires a new level of trust between patients and the health professionals and organizations that serve them.

It has been claimed that PHR offers patient-empowering features such as the capability for patients to view and annotate their health records. PHRs will also help to support the provision of information connected with patient health promotion and healthcare processes.

The Personal Health Working Group of «Connecting for Health» (34) has identified seven attributes of PHRs:

1. Each person controls his or her own PHR.
2. PHRs contain information from one's entire lifetime.
3. PHRs contain information from all health care providers.
4. PHRs are accessible from any place at any time.
5. PHRs are private and secure.
6. PHRs are «transparent»; individuals can see who entered each piece of information, where it was transferred from, and who has viewed it.
7. PHRs permit easy exchange of information with other health systems and professionals

The functionality of a PHR may vary from a simple web-based interface for interactive data entry and data review up to a much more powerful system additionally supporting electronic data/document communication between clinical information systems of primary care practitioners or hospitals and even reminder based support for the empowered citizen, to actively take care of his health, based on relevant disease management programs.

The growing interest in PHRs has led to the development of national level as well as smaller scale initiatives across Europe. The main purposes of introducing PHRs have been to empower patients with a sense of ownership of their care and to improve communication, between both patients and clinicians, as well as between different clinicians involved in that person's care.

According with Jones (2003) (35), patient participation in Electronic Health Record creation can significantly broaden the range of healthcare

(34) *Connecting for Health*, is a private-public collaborative of more than 100 organizations funded by the Markle and Robert Wood Johnson foundations, has conducted the most comprehensive review and analysis of PHRs in the United States

(35) Jones TM. Patient participation in EHR benefits. *Health Manag Technol.* 2003 Oct; 24(10):64, 63.

information in the record and, ultimately, improve clinical decision support. Web-based access, self-service management, consent delegation and agent permissions management are just a few of the features that will encourage active and positive patient involvement with their healthcare records and with their own health management.

The issue of patients viewing and controlling their Electronic Health Record (EHR), and of the issues that an EHR would raise in terms of patient empowerment are being object of growing research (36).

The integration of the PHR with on-line health information facilitates the generation of education materials for consumers (37).

Electronic personal health records (ePHRs) are a relatively young technology with limited but growing use.¹ At their most basic level, personal health records (PHRs) are tools that allow individual patients or citizens to manage their health information. There are several models of ePHRs, all of which have a common goal (i.e., to provide patient access to personal health data to support personal health management and enable sound decision making). But they do vary in terms of the technologies or applications used, the kinds of functions offered (e.g., basic information management [ePHR], how they are integrated for full interaction with health care professionals [eiPHR]), and the source and types of data in the record. Considerable progress has been made in advancing the concept of ePHRs but there is still ambiguity surrounding their form and function.

4.4.4. Self care management tools

New e-technology tools introduced by the growing patient empowerment movement is driving a new generation of self-care by allowing patients to manage their own health. There are a number of illnesses, such as diabetes, in which the decisions most affecting the health and well being of patients are made by the patients themselves. Many of these decisions involve routine activities of daily living (e.g., nutrition, physical activity). It is known that a high percentage of patients with chronic conditions fail to take their medicines properly. In diabetics alone, 20% with type two diabetes forget to take their medicines at least once a week, whilst around 80% are unable to

(36) Munir S, Boaden R. Patient empowerment and the electronic health record. *Medinfo*. 2001;10(Pt 1):663-5.

(37) Doupi, P. (2005) Personalized Patient Education and the Internet: Linking health information to the Electronic Patient Record. STEPPS in burn care. STAKES Research Report 152. 193pp. Finland

test their glucose even once a day because they have not obtained enough testing strips (38).

A primary focus of self-care interventions for chronic illness is the encouragement of an individual's behavior change necessitating knowledge sharing, education, and understanding of the condition.

The use of the Internet to deliver Web-based interventions to patients is increasing rapidly. In a 7-year period (1996 to 2003), there was a 12-fold increase in MEDLINE citations for «Web-based therapies.»

For chronic conditions it is emphasised the importance of self-care in managing long-term disease and in the case of the elderly the support for independent living. Research results show self-management of chronic conditions leads to improved psychological well-being, reduction in pain and lower levels of depression, enabling a better quality of life. In addition, training in self-management programmes at early stages of a condition may help prevent the onset of compounded conditions and further disability.

For patients to take control of their condition, they need good information services - at the right time and in the right form. This will need to include well-validated references and websites for further information, and translation facilities, where appropriate. Advice and support on how to *use* the information is crucial if patients are to be able to make fully informed decisions about their care. Patient-held records can also facilitate self-care.

Effective care requires patients and health care professionals to collaborate in the development of self-management plans that integrate the clinical expertise of health care professionals with the concerns, priorities and resources of the patient.

4.4.5. e-Chronic Care Platforms

It refers to ICT support for communication and coordination among the heterogeneous network of actors involved in chronic disease management.

(38) The Expert Patient – a New Approach to Chronic Disease Management for the 21st Century. www.ohn.gov.uk

4.5. eHealth tools versus Patient empowerment

The capabilities of the different eHealth applications and tools to support patient empowerment actions are variable. Table of Annex 2 displays the different types of eHealth tools we have identified versus patient empowering mechanisms they can likely support.

For example, SMS mobile messages are used for communication of patients with healthcare providers (remainders on appointments, vaccinations, blood donors call, transplantation, etc.) as well as for communication between members of patient communities, and for supporting the management of self-care and chronic care programs.

On other example, an eHealth platform to support chronic care management, typically provides also support for communication with health agents, health information, patient education, decision aids, and self-care.

5. eHealth for patient empowerment in Europe

5.1. General

This section aims to obtain an overall picture of the current implementation of eHealth applications pertaining to this Priority Topic Cluster 2 across Europe. The study reviews the initiatives from the EC and from Member States. The objective is to obtain details from practical experience obtained by the implementation of relevant eHealth services and tools. The selection of «cases» has been according to criteria developed in previous sections for the identification of Patient Empowerment eHealth applications and tools.

5.2. Initiatives of the EC

The European Commission, DG Information Society, declared eHealth as a priority in e-Europe 2002 and e-Europe 2005 following the strategy of Lisbon.

EC has recognized the relevant role of online health information for the general public in the current public health work programme as well as the eEurope 2005 Action Plan.

In addition, the importance of Health Information and the proper usage of eHealth tools is present at DG SANCO initiatives. «Improving health information and knowledge» is the first strand of the EC's current Public Health programme (2000-2006).

The Commission has been very sensitive to the need for quality-proofed and accessible health information. In 2004, the EC recognized that a «growing number of people are looking proactively for information ... and want to be actively involved in decisions related to their own health» (39).

The «Health Information» strand of the Public Health Programme deals with a wide range of issues such as development of health indicators,

(39) EC (2004 a). E-Health. Making healthcare better for European citizens: An action plan for a European e-health Area. Communication from the Commission to the Council, the European Parliament, the Economic and Social Committee and the Committee of Regions, Brussels.

analysis and reporting on health or dissemination of health information, mostly focusing on health information for public health professionals and organizations.

In the context of its Public Health Programme the EC has launched a European Union public health portal (40) on the 12 May 2006, with information «relevant to European citizens». This Portal is structured thematically, mainly addressing to the general public, with a special section for professionals. It intends to help also policy-makers to follow the health activities at European level. The portal is intended to collect and provide quite all relevant links to areas of health activities and on most health-related topics in the EU. The European Commission expects it to be trustworthy, transparent and an easily accessible source of information. Current version is only in English, the other languages are not yet available.

A paper produced in the context of the European Health Policy Forum (EHPF), pointed out the importance of health information for the empowerment of citizens. In their latest position paper of 9th march 2005 («Recommendation Paper on Health Information»), the working group on health information encourage the Commission to develop a more coherent and comprehensive approach to health information provided in the EU. For this purpose, the EHPF proposes a policy mapping exercise to identify all EU initiatives and policies addressing health information, as well as a consultation with key stakeholders (providers and user of health information) (41).

5.3. EU funded research Projects

Research constitutes traditionally one of the main strategic lines of action of EC in the eHealth domain. The EU Information Society Technologies program (IST) has supported a number of projects relevant for eHealth in Patient Empowerment (Priority Cluster 2). Also eTen and the Health Program have founded projects. The Table in Annex 3 displays the identified set of these projects.

(40) <http://health.europa.eu/>

(41) http://europa.eu.int/eur-lex/en/com/cnc/2001/com2001_0529en01.pdf. http://europa.eu.int/eur-lex/en/com/cnc/2002/com2002_0667en01.pdf

5.4. Projects from national initiatives in EU countries

5.4.1. List of eHealth implementations for Patient Empowerment in EU Countries

There are a great number of eHealth applications implemented in EU countries claiming to be developed for patient empowerment support. The following Table displays a list of selected cases across EU countries. Each entry includes eHealth patient Empowerment type according with the criteria discussed in the previous chapter. The list, containing 80 entries, has not intended to be exhaustive but representative enough to allow the analysis of the overall situation in EU countries.

5.4.2. Overall situation

As commented above, the sample of the 80 cases identified for Cluster2 eHealth applications is not exhaustive but offers a good base for the qualitative analysis of overall situation across EU. The Table resumes the types of eHealth applications included in the collected sample.

It can be observed that the applications based on web technologies (category L2) represent more than the half (53%). It is logic because Health Web Sites and Health Portals have constituted traditionally the most referred applications for patient empowerment. The crisis of Internet «boom» represented the disappearance of many «.com» private initiatives in the world. However, the public initiative in Europe has maintained an increasing number of web sites and health portals that provide interactive services including medical advice.

The e-mail is used as a common resource by the people (patients, doctors, managers, health agents, etc.) that have access to Internet. However, no specific «health e-mail» service has been identified in Europe as compared with US where exists some private commercial initiatives, such as Healthyemail (42). Certainly, Health Portals and other web based applications include e-mail services as a means to facilitate communication of patients with health agents and health services. The case is that, in

general, e-mail is not established as a routine service to communicate patients with doctors.

Mobile data services, particularly SMS messaging, are increasingly being used because the universal access for quite all the population. Existing Health SMS are reported to be used in applications such as for patient reminds for appointments, vaccination, notices to blood donors, and so on. SMS applications is actually one of the more dynamic areas. Also, mobile ICT platforms are increasingly used to implement new applications according with the growing availability and speed of mobile IP services. Mobile services are in the core of most new developments addressing personal self-care and chronic care.

It can be observed a growing number of initiatives for implementing Personal Health Records (PHR). PHR present high potentials for patient empowerment. In contrast, e-appointment and e-prescribing applications are more health management oriented and are basically driven by the healthcare organizations to improve system efficiency and costs containment.

Systems to support chronic care management present a vigorous development in line with the wave of health changes to implement new chronic care models.

6. Discussion and Critical Review

6.1. General

Patient empowering is based on the premise that people have the right to make their own choices about their health care. Empowering patients is one of the central elements of healthcare change discourse by the European national health authorities and by the EC. The rhetoric of policy makers is that citizens should take more responsibility for their own health to improve overall health results and to moderate expenditures.

This movement has been accompanied last years by the vision of eHealth as the necessary infrastructure to achieve health policy objectives and for improving the quality and efficiency of national/regional healthcare systems.

Although there has been an increasing use of the term «empowerment», the word is sometimes employed uncritically and in inappropriate contexts. In particular many descriptions on advantages of eHealth applications quite often claim «patient empowering» features without proper concept usage neither objective support.

Patient empowerment is a philosophy inspiring policies and services organization. There are different implementation mechanisms that, as discussed in Section 4, can be supported by eHealth applications and tools. However, not all e-Health systems serve properly to patient empowerment objectives. In fact most of e-Health applications have been developed primarily to support organizations and professionals, not for consumers. The development of eHealth applications intended for patient empowerment requires a specific approach including a collaborative organizational culture, recognition of patients as partners, and to pay much attention on human factor elements.

Patient empowerment involve complex aspects concerning the reality of changing the balance of power in health care, awareness of types of knowledge and the ways in which power may consciously or subconsciously be used. Additional aspects to consider are the awareness of the financial and political aspects of health care and how these affect patient choice.

The popularity of the concept of patient empowerment has emerged within a context of general concern for healthcare spending and increased transfer of responsibility for healthcare to individual citizens. Patients are

increasingly being required to do more of the work of their care, whether or not they want this.

One traditional sensible point on eHealth technologies deployment is the potential impact on the physician-patient relationships. This issue becomes central when dealing with patient empowerment oriented applications.

Especial attention merits the problems for disadvantage or vulnerable populations with accessing care and special needs. In addition those groups usually must save also the «digital divide».

6.2. Reviewing «patient empowerment» underlying principles

As it has been noted before, care must be taken when implementing eHealth applications on inaccurate or poorly supported assumptions behind the notion of patient empowerment. These include ideas such as for example: patient want to be empowered; empowerment is good for patients; healthcare providers support patient efforts to become empowered; informed patients are empowered patients; informed and empowered patients take better care of their health, and other similar ones.

Shared decision-making and patient involvement are often defended as the ideal models of treatment decision-making in medicine and this concept has received much attention in research and clinical practice literature. However, there is a great deal of variability in patients' desires for involvement in treatment decision-making. Sometimes, particularly at times of great vulnerability, people might not want the control that «patient empowerment» is intended to provide them. In fact, patients show different attitudes regarding the involvement in decisions about their own care. Patient preferences vary with age, socioeconomic status, illness experience, and the gravity of the decision. These factors act on «motivation» to employ eHealth tools for patient empowering (See discussion on ACM model at Section 7).

6.3. Current status and trends on implementation of eHealth patient empowerment in Europe

Patient empowering is in first line of the principles inspiring health policy at Member States and the EC. Linked to the overall development of eHealth it can be detected a growing number of applications aiming to support patient empowerment policies. Implementation level vary depending on country and on the type of application, many of them at an incipient degree of development and users adoption.

Previous Section 5 includes a quite wide set of identified eHealth patient empowerment applications in Europe. It is not an exhaustive list of all existing implementations but the collected 80 cases offer a good reference to obtain an overall vision on the current situation and trends of the Priority Cluster 2 in Europe.

The analysis of the collected cases permit us to identify the lines of activity discussed in the following paragraphs.

6.3.1. Providing people access to trusted medical information and advice.

This line of applications have constituted the main core of traditional applications for patient empowering linked to the development of Internet. It includes the implementation of health of call centers and web portals operated by National/Regional Health Services. In this line it is inscribed also the EU Health Portal initiative.

It can be considered a consolidated approach with good implementation examples. They tend to incorporate additional services for supporting patient education, decision aids and tools to support changing behaviour.

In addition there are a relative high volume of initiatives using sites for information provision that are supported by a variety of actors, mostly of them from non profit organizations.

Quality of contents have been in the center of preoccupation of the EC and Member States.

A basic element for patient empowerment is to facilitate the communication of patients/consumers with all the variety of actors involved in healthcare services provision and management. The direct patient/physician communication by electronic means remains a case for analysis. (see a more detailed discussion in dedicated paragraph below).

6.3.2. Supporting patient education for health literacy

Patient education is recognized as perhaps the most important action to proceed for Patient Empowerment development. This group includes not only formal health education programmes using e-Learning, but also online support groups and electronically supported decision aids. Spite of its relevance, the diffusion of eHealth tools in this domain remains in relative modest levels of implementation.

The development of patient personalized health education is an area that merits for further research.

6.3.3. Facilitating the process of accessing and managing own health data

Personal Health Records (ePHR) are attracting much interest in Europe in line with developments in USA, Canada and Australia. The European scenario is dominated by the public initiatives led by some National/Regional Health Services. Thus there is a close connection with eHealth strategies particularly with Electronic Health Records deployment programmes. A few private initiatives also are present in Europe

ePHR presents high prospects for future development, being observed as a basic component for implementing Self-Care and e-Chronic Care platforms.

6.3.4. Increasing Patient Health Security and Convenience

The implementation of e-Prescribing applications is central to eHealth strategies in European countries. Some large scale implementations are actually working or are in advanced phase of development in Europe. (This type of applications form part of Priority Cluster 1).

Regarding patient empowerment, implemented e-Prescribing systems are claiming benefits of saving time and displacements to chronic patients that can request online prescription refills, as well as providing means to protect patients against errors and adverse events. These applications may serve to increase patient convenience while reducing costs and facilitating healthcare services management.

On the other hand, e-Appointment applications enable people to schedule and cancel appointments by electronic means. It is well known that scheduling patients with health care providers and assuring a smooth patient flow through the clinic consumes much time and energy. Several scheduling models have been devised to deal with this critical issue, but almost all these models, in one way or another, have reflected typically the health care provider's point of view to decide who needs urgent care and who needs a scheduled appointment. It has been proposed some new approaches such as «convenience care» to indicate that the patients evaluate their needs and schedule an appropriate kind of appointment, moving the mindset from the provider side to the patient side. Different e-Appointment applications may offer different levels of patient empowering depending on the underlying management model implemented.

It must be noted that both type of applications, e-Prescribing and e-Appointment, are in the core set of eHealth infrastructures included in most national/regional eHealth strategies in EU countries.

6.3.5. Developing online behavioral modification tools (self-care)

It is noted a growing interest on the implementation of eHealth tools supporting health policies addressing the adoption of healthy lifestyles by general population.

These health policies are being actively impulsed by the EC and the Member States. Smoking cessation and weight loss are in the forefront of public health programmes, that are also accompanied by legal and regulatory measures.

The change of health behaviour requires a strong effort in people education, information provision and supportive tools for adherence to therapy programmes.

The revision of European experiences shows an interesting collection of activities connected with self-care. They exploit the capabilities of web technologies but also of telephone and mobile communications.

The trend in the implementation of this type of eHealth applications seems to converge with ePHR and with integrative platforms for chronic and elderly care.

It is very important to relay on the primary care physicians to support the adoption of this kind of eHealth tools.

6.3.6. Supporting new models for chronic care

There is a general effort in EU countries exploring new healthcare provision models to improve current situation of chronic care and to afford the demands driven by a growing elderly population.

It is generally recognized the potential of ICT to provide solutions for better and more accesible healthcare provision to patientes with chronic illness. In fact during last years many research demonstrators and pilot projects have been developed in the context of European RTD FPs and by national initiatives.

However, analysis reveals most developments have been technology driven, and very few being really linked to the real implementation of a chronic care model incorporating patient empowering philosophy.

Regarding practical implementations of eChronic Care in Europe there are relevant cases of implementations on more frequent chronic illness, as i.e. diabetes, hypertension, thrombosis risk, respiratory diseases, dementia, and others.

The type of involved technology varies from the simple telephone or SMS messaging based systems to complex IT and communication platforms (eChronic Care Systems) supporting communication and coordination among the heterogeneous network of actors involved in chronic disease management.

For example one referred aplication use the telephone and a personal identification number for chronically ill patients to telephone in with updates on their progress. Relevant information collected is then reviewed by doctors who decide whether or not any medical. Other case is a service which allows diabetic patients to submit glucose readings by SMS and to receive physician feedback via the same method. Similar systems are used for follow up and control of patients with hypertension and to report blood reading from coagulation risk electronically to facilitate accurate and effective use of anti-coagulation medication.

An increasing line of activity refers to remote monitoring to enable elderly persons to continue to live in their own homes. Sensors located in their homes can monitor any physical signs which need to be kept under review, and these are monitored by a central medical service or virtual care centre. If necessary patients can connect patient directly to doctors and nurses who give professional advice and decide on any future action. These initiatives are connected with AAL (Ambient Assisted Living) and they respond to an integrative approach of providing healthcare and social home services for the elderly and the chronic ill.

According with that, the trend of actual situation in Europe shows eHealth chronic care empowering tools are shifting from some simple self-

care passive, information, and decision aids provided by web sites, to complex integrated collaborative platforms for e-Care personal health services, involving advanced medical informatic tools, biomedical instrumentation, and fixed and mobile communication systems.

6.4. Discussion on the main sub-Cluster 2 domains

6.4.1. Consumer Health Communication. The case of patient/physician communication

Regarding patient/physician communication current experience covers the use of «Telephone», «conventional e-mail», and «secure health messaging system».

Despite its potential, the use of e-mail for physician-patient communication has not been widely adopted (43). The current reality shows that only a select group of physicians and patients might be ready to use e-mail for health care purposes. Though quite all physicians use e-mail for personal and professional purposes, they were concerned about using it for direct patient health-related communication.

Recent studies show telephone consultation with own doctor is much more common than e-mail consultation; more than one-quarter (28.4%) of the population have had a telephone consultation but only 1.4% have consulted by e-mail. This situation is general in all EU countries (44).

Some studies have surveyed the nature, prevalence, and risks and benefits of patient-physician e-mail aiming to advance in the critical evaluation about what is required for it to become a truly transformational technology (45). Assessment of physicians' use of and attitudes toward electronic mail (e-mail) for patient communication are contradictory. Studies on the experiences of physicians who are early adopters of the technology showed that, despite their daily use, a part of them were not satisfied with physician-patient e-mail. Dissatisfied physicians reported

(43) Houston TK, Sands DZ, Nash BR, Ford DE. Experiences of physicians who frequently use e-mail with patients. *Health Commun.* 2003;15(4):515-25.

(44) E-User Project. <http://www.euser-eu.org/ShowCase.asp?CaseTitleID=881>

(45) Freed DH. Patient-physician e-mail: passion or fashion? *Health Care Manag (Frederick)*. 2003 Jul-Sep;22(3):265-74.

concerns about time demands, medicolegal risks, and ability of patients to use e-mail appropriately (46) (47).

Like all technologies, use and misuse of patient-physician e-mail will determine at large whether its possibilities will become an extended tool. Most of the barriers are not specific of the health domain but of society in general about consumer access to technology and e-literacy as discussed in the next Section 7.

6.4.2. The access of consumers to health information

The access of health information by patients is a complex process that depends on several factors including: contents; quality of information; patient preferences; patient literacy; care provider preferences and capacities; information needs and media of communication (48). The interface is as important as the content in enabling patients to benefit from the access to information.

The access of consumers to health information is conditioned by technical and information literacy skills. For those who have access, there is not conclusive evidence of the result in them becoming empowered in their health care because the use of health information obtained on the Internet (See discussion on ACM model in next Section).

According with the results of e-User Project, it has been detected an increase of the use of Internet by adult population to search health information from the 19.1% in 2002 till the 30.6% in 2004. In the countries surveyed, the Internet is already the system preferred the most important method of looking for health information for 17.2% of the adult population overall, and for 28.2% of people who ever search for health information from any source. In some countries (Denmark, Ireland and the UK) its importance is much higher.

One in fourteen (7.3%) of the population in the countries surveyed have used the Internet in preparation for a visit to a doctor (this rises to

(46) Gaster B, Knight CL, DeWitt DE, Sheffield JV, Assefi NP, Buchwald D. Physicians' use of and attitudes toward electronic mail for patient communication. *J Gen Intern Med.* 2003 May;18(5):385-9.

(47) Hussain N, Agyeman A, Das Carlo M. Access, attitudes, and concerns of physicians and patients toward e-mail use in health-related communication *Tex Med.* 2004 Mar; 100(3):50-7.

(48) Shaller D. Consumers in health care: the burden of choice. [Report prepared for: California HealthCare Foundation]. 2005 October.

almost one-in-seven in Denmark, Ireland and the UK); one-in-seven (14.4%) of the population have used the Internet to get more information as a follow-up after a visit to a doctor (this rises to 30.5% in Ireland. Most (92.5%) of those who have used the Internet as a source of health information say that it has made them more informed about health matters; overall, 28% of the population say that they have become more informed about health matters through the Internet. Up to one-in-five of users say that the information they have found on the Internet has informed their decision-making about health matters or encouraged them to change health behaviours.

Telephone-based health information services are also used, but by fewer than one-in-ten (9.1%) of the population in the countries surveyed; telephone-based services are especially important in the UK, being used nearly as much as online services (49).

The most relevant sources of health information for European citizens are «official» Portal sites that provide also other additional services. These websites tend to be provided by the government directly or health care agencies. The aim is to provide information and advice about health, illness and health services, to enable patients to make decisions about their healthcare and that of their families. These Portals are tending to act coordinated with other information channels like telephone (call centers) or TV channels. A very representative example is an NHS On Line. Data published very recently (50), is very illustrative of the performance of this kind of service. NHS Direct's website (51) had last year 13.5 million users representing an increase of around 30% from 2005. Over the same period the number of people calling the phone service took around seven million calls in the year, a reduction of around 15% from 2005. For example, over the ten day Christmas holiday period, the service received almost 250,000 phone calls and 340,000 website visits. The busiest days for phone calls were Saturdays 23 and 30 December with nearly 35,000 calls each day. According with the provided data, throughout the holidays, the service began triage on 96 per cent of urgent cases within 20 minutes.

The similar seervice in Scotland, NHS 24 answered 93,436 calls, compared with 81,583 in 2005.

As well as the phonline, and the website, the NHS Direct Interactive Digital TV service includes 3000 pages of information on 500 health topics and is available to almost 15 million cable, satellite and Freeview viewers.

(49) <http://www.euser-eu.org/ShowCase.asp?CaseTitleID=881>

(50) <http://www.e-health-insider.com/news/item.cfm?ID=2388>

(51) <http://www.nhsdirect.nhs.uk>

6.4.3. Virtual Communities

It is widely accepted that virtual communities may empower patients and enhance coordination of care services (52). However, there is not sufficient systematic evidence of the effectiveness of virtual communities on clinical outcomes or patient empowerment. When practitioners utilize virtual community tools to communicate with patients or colleagues they have to maximize sociability and usability of this mode of communication, while addressing concerns for privacy and the fear of de-humanizing practice, and the lack of clarity or relevance of current legislative frameworks. Patient empowerment application in real world implies ethical challenges including the concepts of identity and deception, privacy and confidentiality.

There is no proved evidence to support concerns over virtual communities harming people (53). However, given the abundance of unmoderated peer to peer groups on the Internet, research is required to evaluate under which conditions and for whom electronic support groups are effective and how effectiveness in delivering social support electronically can be maximised.

6.4.4. Personal Health Records

Electronic personal health records (ePHRs) are a relatively young technology with limited experiences in use but growing expectancies. At their most basic level, personal health records (PHRs) are tools that allow individual patients or citizens to manage their health information. There are several models of ePHRs, all of which have a common goal (i.e., to provide patient access to personal health data to support personal health management and enable sound decision making). But they do vary in terms of the technologies or applications used, the kinds of functions offered (e.g., basic information management, how they are integrated for full interaction with health care professionals Health Records Systems, and the source and types of data in the record).

Electronic Personal Health Records (ePHR) implementation in European countries is still in its early stages. The analysis of current

(52) Demiriz, G. «The diffusion of virtual communities in health care: concepts and challenges» *Patient Educ Couns.* 2006 Aug;62(2):178-88. Epub 2006 Jan 6.

(53) Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ.* 2004 May 15;328(7449):1166.

experiences suggest that current ePHR implementers are adopting a simple ePHR model. It is not clear at this point whether the ePHR systems will evolve into more comprehensive models that enable electronic interaction between patients and health care professionals.

According with the reported cases in Europe (section 5), ePHR systems are provided by a number of entities ranging from public healthcare services to private health insurance groups. However, real implementation coverage is very low and very few Europeans have access to such personal health record systems today.

Limited commercial offerings exist allowing patients to create their own ePHRs, but data on the number of subscribers to these services are not available, so their scope cannot be assessed in detail.

Countries that plan to provide ePHRs as part of their national eHealth information systems have control over the data that will be offered to consumers and seem to be focused on the ePHR model of offering access to information with little attention to potential for changing care delivery approaches in the near term.

Further to national scopes, the European challenge is to enable the existence of ePHR systems that can be used across countries.

It has been often assumed that a majority of patients wish to be empowered through viewing their health record, but some studies shows most prefer to use paper rather than an electronic medium (54). According with these studies, a significant number of patients do not want to control their health record. It has been found that age and level of education had a significant impact on a patient's desire to be empowered and their desire to view their health records.

The experience in US shows also low rate of adoption by consumers. Of the 27 PHR-like tools identified in a November 2000 study (55), only seven (26%) were still accessible in May 2003. The main reason for this high rate of failure was the lack of a sound business model for these systems. Specifically, people were not willing to pay to use these systems.

A recent study by Earnest (56) evaluating a clinical trial of patient access to an online electronic medical record found that all participating clinicians, despite initial misgivings, later believed that the process had been

(54) Munir S, Boaden R. Patient empowerment and the electronic health record. *Medinfo*. 2001;10(Pt 1):663-5.

(55) Dean Sittig, (2001) Northwest Permanente & Kaiser Permanente Center for Health Research.

(56) Earnest M, Ross S, Wittevrongel L, Moore L & Lin C. «Use of a Patient_Accessible Electronic Medical Record in a Practice for Congestive Heart Failure: Patient and Physician Experiences.» *JAMIA*. Vol. 11, 2004:410-417.

empowering for patients and supported the idea of providing access to electronic records.

Ross and Lin (57) note that the most consistent finding across studies of patients having access to their medical records is the enhanced patient/physician communication. In turn, better communication would improve trust, which Kirshner (58) cites as «perhaps the most significant and influential component of the patient-doctor relationship.» Winkelman (59) contends that trust motivates self-care and is central in determining whether a patient merely «looks at» or «uses» his or her medical records.

Long-term outcomes await the usage and evaluation of the PHR on a broader scale. Regardless of the future evolving path of the PHR, its success, relevance and usefulness would relay greatly on the human factors such as users involvement in design and development as well as on the alignment with trust relationships between patients and physicians.

Regarding the situation in Europe there are relevant examples illustrative on different strategies and approaches. For example, the situation in England is going along in planning and implementation, with the expectation of offering an ePHR as part of its ambitious national health IT program. It has placed a strong emphasis on public engagement. The Connecting for Health has developed a two-phase plan for offering individuals access to their personal health data. The first phase involves HealthSpace, a secure place on the Internet where people can store personal health information. Patients will have their own personal online health organiser in HealthSpace. This will act as a calendar, allowing them to record appointment details and set up reminders. It will also enable them to keep a record of their blood pressure, weight and height. It will store self-care programmes on, for example, stopping smoking or managing diabetes.

HealthSpace will incorporate a search feature, allowing patients to look for up-to-date, reliable health-related information, and offer guidance

(57) Ross S & Lin C. The Effects of Promoting Patient Access to Medical Records: A Review. *JAMIA*. Vol. 10, No.2, Mar/Apr, 2003:129-138.

(58) Kirshner M. The Role of Information Technology and Informatics Research in the Dentist-Patient Relationship. *Advances in Dental Research*. Vol. 17, December, 2003:77-81.

(59) Winkelman W, Leonard K & Rossos P. Patient-Perceived Usefulness of Online Electronic Medical Records: Employing Grounded theory in the Development of Information and Communication Technologies for Use by Patients Living with Chronic Illness. *JAMIA*. Vol. 12, 2005:306-314.

Winkelman W & Leonard K. Overcoming Structural Constraints to Patient Utilization of Electronic Medical Records: A Critical Review and Proposal for an Evaluation Framework. *JAMIA*. Vol. 11, 2004:151-161.

and information on healthy lifestyles (60). HealthSpace is currently available for NHS patients (61).

Following NHS plans, in the second phase, patients will eventually be able to access their own electronic health records via a secure Internet link to the NHS. They will be able to check their record for accuracy and, in time, will be able to add their treatment preferences and information about their needs, such as wheelchair access requirements (62). Patients will be able to access their national summary record beginning in 2008.

It must be noted that some works outside the centralized IT program in UK are beginning to result in patients with chronic conditions able to access their information online (63).

In a similar line Scotland's national health information technology strategy seeks «to deliver an Integrated Care Record jointly managed by patients and professional NHS staff with built-in security of access governed by patient consent» (64).

Experience with the SUSTAIN system in Sweden has revealed specific issues that ePHR developers must take care. According with the reported data the availability and complexity of the technology used to support the ePHR is a significant factor in the success of ePHR systems.

Also, citizens may need education on the benefits of ePHRs to prompt their participation (65). Citizen proficiency with the the technology used and the ePHR specifically may be a barrier to effective use. Regular users (i.e., those with chronic illness) may be more likely to achieve and maintain proficiency than will infrequent users (i.e., generally healthy individuals).

It is important the remark that a national patient identifier becomes basic for the implementation of a national ePHR system.

Finally, if the ePHR is not part of a national health system, then the issue of how to pay for it is critical.

There are limited examples of ePHR commercial developments out of the national/regional Health Systems. Examples are MediBANK (Spain) (66) linked to a network of private hospitals; EMMS International (UK) that offers Global Health ID (67), and LifeSensor from ICW (Germany) (68).

(60) Connecting for Health, 2005e, 2005f.

(61) www.healthspace.nhs.uk

(62) Connecting for Health, 2005.

(63) <https://www.renalpatientview.org>, E-Health Media, 2005.

(64) NHS Scotland, 2004.

(65) Eklund & Joustra-Enquist, 2004).

(66) www.medibank.es

(67) <http://www.pemms.com/solution?>

6.4.5. e-Chronic Care

Chronic Care is receiving a growing attention by health authorities in European Countries. The implantation of new care models is being accompanied by the demand of appropriate ICT tools to support the processes.

The growing number of elderly people in Europe will be producing increasing demands for chronic care to the health care systems in all countries. Current social policies also seeks to enable people to maintain their independence and self-sufficiency in all circumstances and stages of their lives for as long and as far as possible. Many efforts are being directed to implement new healthcare alternatives intended to improve health and the quality of living conditions of the elderly. This involves an increase in extramural individual care, often referred also as home care. The objectives are to satisfy people's needs for health but in a comprehensive way considering safety, care and comfort in so far as these services contribute also to the recovery and maintenance of their health and their quality of life while living on their own home and enabling them to continue participating in their community as far as possible.

Nevertheless, up to date experience has been most produced on dedicated systems driven from the healthcare provision needs.

Most of the implemented experiences correspond to the «Disease management» model for patients management. They are characterized by a coordinated and proactive approach to manage care and support for patients with chronic conditions in which self-care efforts are relevant. It emphasizes prevention of complications utilizing evidence-based practice guidelines and patient empowerment strategies.

Target population includes patients with chronic illness but also people who have multiple hospitalizations and high emergency services use. Chronic conditions most usually addressed by disease management services are: diabetes, congestive heart failure, asthma, HIV/AIDS, cancer, obstructive pulmonary disease. By using proper monitoring devices and instrumentation, it is possible to facilitate management of therapeutic plans and medication following-up patient status and trends with a suitable frequency. The monitoring of patient's health condition allows a healthcare professional to intervene timely preventing acute care intervention in many cases. It is very important the role of the physicians. An study from the Markle Foundation's Connecting for Health concluded that disease management applications that encouraged patients to enter very detailed information pertaining to a single chronic condition may provide some immediate benefit to users, but «simply offering people a means of recording information on a daily basis does not make them

better managers of their health or health care. Without a clinician at the other end of the application continually providing advice, making modifications to prescriptions or otherwise providing them with some ideas to help better manage their condition; these systems were doomed to fail» (69).

The design of e-Chronic Care systems requires a strategic vision on system interaction with final users to effectively accomplish the intended objectives.

In connection with this it is interesting to note that many projects and implementations are nowadays making emphasis on automated control. Thus, following this idea many designs are directed to create smart user environments that eliminate the need of the patient to perform as much as possible tasks. This type of systems usually act automatically avoiding the patient intervention unless emergencies. These systems can be useful and appropriate in some conditions and for some patients but not always is the better solution. A basic problem is the more complexity the algorithms consider when making decisions, the less transparent these decisions will be to the user. The system will actually become less predictable as it acquires more expertise, and the user will be left feeling frustrated helpless to understand the system behavior. Examples of this approach are projects incorporating smart sensors and electronic decision systems that take decision on alerting or generating «orders» for patients and caregivers or even taking therapeutic decisions (i.e. insulin injection)

In other other alternative solutions the system should require human effort in ways that keep life as mentally and physically challenging as possible as people age. This systems are more close to the implementation of patient empowerment strategies.

It seems reasonable to think that general systems would include different control loops at different task levels, including some automatic computer based controls but also other requiring the active patient intervention.

An important concept dealing with chronic care is the trend to personalized services. In this context, ICT allows one variety of services can be provided in a personalized way by the same platform. Even more, a common ICT infrastructure (standards, protocols, tools) can support different operators providing personalized services according with user profiles and allowing different business models with public, private and mix implementation.

(69) Connecting for Health (Markle Foundation). 2004. Connecting Americans to their Healthcare. Final Report of the Working Group on Policies for Electronic Information Sharing

It is expected that collaborative platforms, such as those implemented for eChronic Care, will strengthen the position of the patient, but it is extremely difficult to predict the long-term implications of this.

6.5. Identified key issues

The implementation of patient empowerment philosophy in the real practice must afford complex issues reflecting the impact on the traditional structures and power relationships, resulting often in contradictory interests of healthcare interested parts. Some of the most relevant issues are the following:

i) Physician must become the main instrument to empower patient

The adoption of the «empowerment» paradigm involves a fundamental redefinition of roles and relationships of health care professionals and patients. Whilst there is no consensus amongst analysts regarding how best to define «patient empowerment», at the very least, this concept entails a re-distribution of power between patients and physicians. However, experience shows physician promotion is key to getting high consumer adoption of patient empowerment tools. It can be viewed as a paradox the situation of the physician as the main actor for educating patients to become empowered. Experience shows physicians receptiveness to patient empowerment is variable depending on a number of circumstances. If eHealth application is viewed as beneficial only to patients, it would be hard to get physician support.

Some studies pointed the evolution of physicians to become mentors that guide patients to exploit capabilities of Internet resources.

Any strategy for widening the use of eHealth patient empowering tools requires a serious approach to physicians role.

ii) Empowered patient educated to become compliant with treatments

One basic objective of patient empowerment actions is to modify patients behaviour to improve the compliance with treatments. This may be contradictory with enabling patient with higher degrees of freedom about decisions about his health. The implementation of educational and communication actions, enhancing patient health literacy, must be accompanied of the possibility of influence decisions on his health management but being compatible with scientific evidence, medical advice and healthcare services availability.

This issue is linked with the above but it is really challenging to insurance and healthcare provision organizations

iii) Changing dependence on persons to dependence on machines

Patient empowerment philosophy represents a modification of actual power distribution in healthcare, but this no means to transfer the power of physicians to computers. Certainly, the use of eHealth for patient empowerment involves electronic means to communicate persons with persons but also persons with machines. eHealth applications for patient empowerment must respect the «independence» of patients by giving them greater choice and control over the way in which their needs are met, not creating new barriers limiting access to healthcare services. Systems should support independence, not dependence. e-Services must help to maintain the independence of the individual. Human interfaces, usability and accesibility are esential. Dependability, including security and reliability must be carefully considered paying attention to risk analysis and management practices.

In any case, the healthcare services are very sensitive to human factors and in spite of the objective value offered by eHealth applications, what many patients in many situations rather prefer is the face-to-face communication with their doctors.

iv) Technology can amplify problems

Technology can help greatly to facilitate the implementation of quite useful patient empowerment actuations. Nevertheless, if not properly used technology may serve as amplifier of existing problems or to create new ones.

Experience shows that one key factor for success is to implement eHealth applications

to support well designed processes and taking into consideration impacts on the organization and all stakeholders.

Change management is of major importance for overall success.

v) Interoperability

Patient empowering applications are not likely to be incorporated into clinical workflow without addressing integration with general eHealth tools such as: Patient Identification Systems, Electronic Health Record, Appointment Systems, Electronic Prescribing, etc.

The evolutionary trend of eHealth patient empowering applications is toward the increase of complexity and the integration of different applications.

This is exemplarized in the case of Health Portals of National/ Regional Health Services that are integrating voice call centers, health information repositories, medical advice, public health information, administrative services, self-care supports, patient education programmes, etc.

Furthermore the implementation of applications for e-Chronic Care integrates data from different information applications such as ePHR, EHR, Patient Identification, self-care tools, e-mail secure system, mobile SMS, telemedicine services, and other allowing effective support for the chronic care new models being adopted.

This means requirements for technical and semantic interoperability but also for organizational interoperability. All these requirements are further emphasized when considering the construction of the EU eHealth space.

6.6. Driving factors

As it has been discussed in the Section 2, «Patient Empowerment» is a movement that receives impulse from social and contextual factors that have been discussed with some detail before.

Several major driving factors are common with general eHealth applications. They are

- EC and National Health policies. Lisbon Strategy. e-Europe. I2010
- EC and National Political impulses (eHealth strategies and deployment plans)
- EC and National RDT Programmes
- Development of Information Society
- ICT technology development
- Global markets drive, specially US.
- International standards

These factors have been widely analysed regarding eHealth deployment in general. In addition to these, the known experience with current systems operation indicates more specific elements acting on favour of extending the wide use of the eHealth applications and tools. They are presented linked to the main actors as resumed below.

Consumer Demand

- Demographic trend to elderly population growth. People with chronic conditions are most likely to need and use eHealth patient empowering applications.

- Patient-provider secure messaging, online prescriptions refills, lab results, medication lists, and disease management plans are seen particularly useful by patients
- e-Health applications for patient empowering makes services more convenient
- Improved quality of life because adherence to healthy lifestyles. Legal and social pressures for behaviour change

Physicians perceived benefits

- Time saving and better time management
- Support to deliver better care with collaborative health educated patients
- More personal mobility
- Professional opportunities. Gaining competitive advantage

Benefits for Health Organizations

- Implement legal mandates (smoke regulation, elderly care,..)
- Implement policy objectives mandated by Health Government or Health Agencies (Health Plans, eHealth plans)
- Fulfill expectations created on population served (public systems)
- Infrastructures and tools to support change
- Implementation of competitive, more effective services for consumers
- Improve resources management
- Reduce costs
- Produce added value for invested IT infrastructures

6.7. Resistances

The pace of implementation of eHealth applications in general must face serious resistances for wide deployment. In particular, the applications analyzed in this eHealth ERA Report on Priority Cluster 2 (Patient Empowerment) present a low rate of diffusion regarding their level of practical deployment and the number of citizens actually involved. This relative slow diffusion is produced because resistances to wide implementation produced by a number of factors.

Logically, patient empowerment applications are subjected to the same general constraints detected for eHealth deployment in general. All of them are well known and they have been largely discussed in the literature

and eHealth working groups. However it seems interesting to mention a number of barriers detected from from the experience cummulated at the reported practical implementations in Section 5.

Barriers at healthcare organizations

- Health care organizations are moving slow to deploy eHealth interactive services. Priorities are primarily set to IT infrastructures supporting Organizations and professionals. Most efforts are being directed to implement needed basic eHealth infrastructures i.e. Hospital Information Systems; PACS; Laboratory systems; Health Messaging; Electronic Health Records, etc.
- Even for applications that can be intended for «patient empowering» (i.e. health portals, e-prescribing, e-appointmenet, ePHR, eChronic Care) quite often the applications are provider minded
- Resistance to organizational change
- Legal and regulatory constrains in health public systems

Barriers from Professionals

- Resistance to the change
- Physicians perceive little incentives to use patient empowering tools. Clinicians remains skeptical to patient empowering
- Physicians fear the loss of authority to health literate patients
- Clinicians show slow adoption of electronic means for communicating directly with patients
- Accesibility of eHealth tools. Lack of implementation of appropriate eHealth applications
- Pressure of assistance. Time constrains
- Need of literacy on e-skills
- The issue of payment for the invested time for on line services
- Fear to legal risks

Barriers from Consumers

- Passivity, lack of motivation. Do not like to assume responsibility
- Need of patient health education
- Resistance to the change of healthcare model. Preference for traditional model based on medication and technology (analitical, xRay, etc)
- Lack of access to Internet. Digital divide
- Lack of ability of patients to use e-Health tools appropriately
- Consumer fears about security and misuse of personal information at Internet

- Lack of appropriate information sources. Concerns on the quality of on-line health information
- Lack of precise information for decision taking and decision aids
- No existence of real choice options
- Lack of services offered by Public Health Systems
- They do not like to pay for e-services

The final impacts of the different driving factors and barriers on the diffusion of the eHealth patient empowering applications vary depending on particular situations at each local context and the type of application.

In the next Section the situation is analysed in more detail from the perspective offered by the ACM model for the different targeted consumer groups. It serves for discussing on strategic action lines suggested for implementation driving.

7. Potentialities and areas for recommended action

7.1. General

This Section is devoted to identify, policy oriented, action lines to work on the wide implementation of eHealthERA Cluster2 for Patient Empowerment as well as opportunities for the cooperation in RDT at EU.

The rationale is supported in the so called ACM model that allows to visualize the different population profiles regarding eHealth services «Access», «Competence» and «Motivation». The recommended actions are aimed to improve along these three ACM axes but also considering the EU eHealth policy in the i2010 context. Elderly care for independent living and wellbeing and e-Inclusion are particularly relevant. Special attention is paid also to the opportunities regarding 7FP prioritized lines and other related actions such as AAL 169.

Following the focus has been on eHealth applications and tools such as Mobile eHealth; ePHR; eChronic Care integrated systems.

It must be emphasized that patient empowerment applications are very sensitive to no technological factors, and that key issues are far more than pure technological ones. Efforts must be paid to modelling processes, collaborative environments, interoperability, security, risk analysis and management, human interfaces and change management.

7.2. The propensity to adopt eHealth for patient empowerment. The ACM model

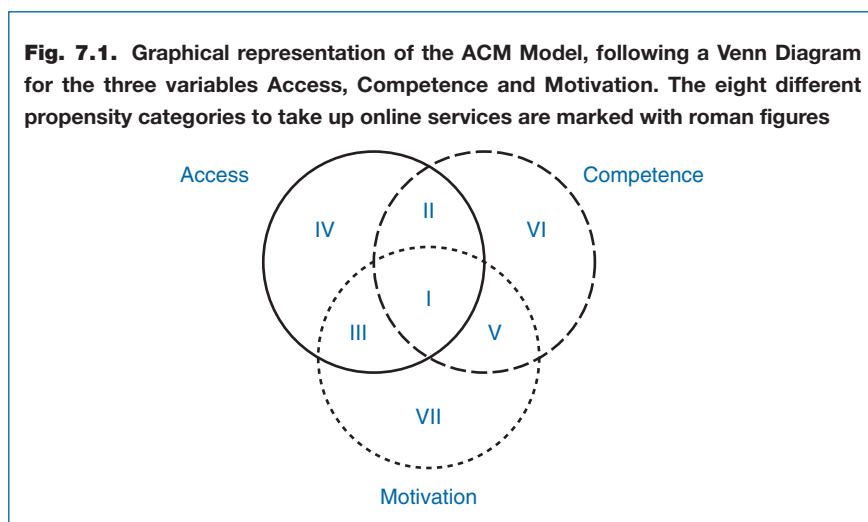
The adoption of eHealth applications by general people is a quite complex process. Recent research on Internet based applications for citizens, has proposed the so called «ACM» model (70) that considers the propensity of patients to adopt e-Services is a function of three main factors: Access, Competence and Motivation. These three factors are defined as follows,

(70) Karsten Gareis (2005): eLearning for Work: The Role of Access, Motivation and Competence in Explaining Uptake. Empirica. <http://www.euser-eu.org/>

Access is the capacity of the user to be electronically connected to Internet services (at home or alternatively sufficiently good access elsewhere), and the no existence of barriers to operate the terminal devices and the user interface because personal limitations or mismatches (accessibility).

Competence reflects the capacity on e-Skills - i.e. the extent to which a person knows how to use computing devices, communication terminals, and Internet at the level needed to use the electronic service. This concept can be extended to include capacity to work with eHealth tools.

Motivation is defined in terms of explicit willingness to use the electronic services in general; and in terms of relative preference for the particular mean for information access (online, face-to-face, postal, phone, mobile).



Maximum propensity for using an ICT on-line application is assumed to apply for persons who have all three: 1) full access to end user devices, 2) the necessary digital skills and experience to use the e-services, and 3) the motivation to use the electronic services instead of more traditional ways.

The ACM model allows to classify potential users according with the eight possible combinations for the three variables Access, Competence and Motivation (considered digital valued variables). This classification allows to estimate how the population is distributed according with the different ACM profiles. The Table below describes these 8 categories regarding the propensity to effective use of e-services.

Table 7.1. Characteristics of the eight propensity types according to ACM model

Group	Description
I (ACM)	Has all three factors - access, motivation and competence. Represents the group of potential users ready to adopt the eHealth service
II (ACM)	Lacks motivation but has access and competence. Efforts to increase motivation may be beneficial for eHealth user adoption. A supply of high-value services, coupled with promotional activities, appears critical.
III (ACM)	Has access and motivation, but lacks digital skills. If mainly technical skills are missing, training in necessary skills is likely to be very beneficial.
IV (aCM)	Only has access, but not competence nor motivation; both motivational and training interventions will be needed. Intermediaries can be expected to play a particularly important role for this group, i.e. household members or friends who are able and willing to provide the required technical help in accessing online services and applications.
V (Acm)	Only access is missing; depending on the circumstances different interventions may be needed, such as financial supports, public access points or assistive technology and accessibility measures.
Vi (aCm)	Only has competence. Measures should be taken for providing access and to motivate
VII (acM)	Only has motivation; will require both infrastructural and training interventions. It should be explored if traditional channels are not more appropriate to provide this group with services.
VIII (acm)	None of the three conditions exist; multi-dimensional interventions will be needed

The ACM model has proved been useful for overall descriptive analysis and policy guiding actions for e-Government and e-Learning domains. It can be used also for Cluster 2 eHealth applications with minor adaptations.

7.3. ACM model characteristics

The ACM model, as any model, offers a simplification of the reality to facilitate the overall analysis and decision taken. However the basic issue is the consistent definition of the variables and the use of the model in a way that can serve for the pretended purpose.

A first consideration is that the three dimensions (ACM) are not independent from each other. For example, people who acquire skills in Internet usage are likely to become more interested in online interaction with e-Services than people without any literacy on computing and electronic communication systems.

In addition, the eight types of user groups result from considering the three variables ACM can adopt only digital values (yes/no). However, in real life, the variables can take continuous values between the two poles. Furthermore, the variables can change dynamically with time at different rates in different socioeconomic contexts.

It must be noted also that the results of using ACM model should differ for the same population depending on the type of e-Health service analysed. For example, it should be different for health information access, than for using ePHR systems or e-Chronic care platforms. This theme deserves further research on social behaviour regarding eHealth technologies adoption. In the meantime we will use the «digital» ACM model for overall analysis.

7.4. Identification of Strategic actions to increase the adoption of eHealth patient empowerment applications

The line of research for strategic action lines has been guided for the improvement along the three key factors: Accessibility, Competence and Motivation.

Table below shows in a resumed way the proposed action lines and the specific actions to promote eHealth applications for patient empowerment. These proposals are based in the following rational:

a) Improving accessibility

The improvement of accessibility is considered in two aspects: i) increasing the population having digital terminals able to be electronically connected,

and ii) increasing the accessibility of user interfaces and other aspects by promoting design for all.

It is important to recognize that access to the Internet is by no means universal. Today, the majority of the population has no access to Internet at home. A recent study from the EC on eInclusion (71) shows low Internet use among house persons (especially women), older citizens, retired people and people living in rural areas. According to Eurobarometer 58.0 the subjectively identified reasons for non-use of the Internet among European citizens are non availability of a PC at home (high cost of PC ownership and internet connection); lack of access at work or at Public Access Points, the complexity of technology and the lack of basic skills (72). The underlying reason, however, could be that people don't use Internet because they are not interested in the information or the services actually provided.

Education and income appear to be the most important variables related with digital exclusion. Statistics show the constant growth of the proportion of citizens having access to Internet that will increase the potential population able to access e-Services in the future. However, at actual pace it should be required several years before a big majority of population would have access to Internet at home in all EU countries. This issue is connected with digital divide and e-Inclusion, being general not specific for eHealth.

On the other hand, practically all the population in Europe uses mobile phones. Thus, mobile services offer the opportunity to implement services that can reach theoretically all population.

Thus, in spite of considering the positive value of any measure improving traditional access to Internet, it seems strategically relevant to work on the development of eHealth applications exploiting the wide diffusion of mobile communications in Europe. Almost all citizens have access to a mobile terminal. Early applications for patient empowerment using mobile data services, as SMS, have shown their potentialities. The growing capabilities and functionalities of the 3G, and the emerging 4G, offer opportunities for new generations of eHealth applications. These future developments can make value on AmI for improving accessibility to information and communication, aligning efforts with the I+D+i priorities at 7FP.

Other strategic line pointed for action is to work on the accessibility of user interfaces and about applying Design for All principles when designing

(71) EC «eInclusion revisited: The Local Dimension of the Information Society» Working document (2005).

(72) EC. Europe's Information Society Thematic Portal. eEurope 2005. e-Health. http://europa.eu.int/information_society/europe/2005/all_about/ehealth/index_en.html

eHealth patient empowerment tools. This aspect is of paramount importance, particularly thinking on elderly and handicapped people in line with e-Inclusion EU policy.

b) Improving Competence

Competence, in the basic ACM model proposal, was defined as Internet literacy. Regarding eHealth for patient empowering we should rather use a broader concept of «competence» embracing ehealth literacy.

In general, the interest in Internet use among elderly and people of lower educational level is significantly lower than among the general public. There is evidence that the literacy level needed to read health information on the Internet appears to inhibit information-seeking efforts of low-literacy adults (73).

Patient education appears as a key strategic line to work on patient empowerment as far as is the way to improve health literacy and consequently «competence» to exploit capabilities of eHealth for his empowerment. In this line of thinking, it is considered that research efforts should be focused on the development of eHealth tools supporting «personalized patient education» as proposed by Duopi (74). This approach includes to make use of ePHR as the base for the personalized patient education. Certainly, ePHR is in his fancy regarding extended adoption, but this represent opportunities for added value application. Early research results in this line are very promising.

c) Improving Motivation

The improvement of citizen's motivation is central for the wide adoption of any eHealth application addressing patient empowerment. The success of any effort to engage patients in their own health must be appropriately targeted to meet individual needs and preferences. The rationale behind the proposal is that people will be more motivated to use eHealth systems that produce him visible benefits solving real actual needs. It is clear that a big current demand is connected with chronic care and elderly care. People are living longer and they are becoming more elderly. The need for chronic care will continue to

(73) Birru, M.S., Monaco, V.M., Charles, L., Drew, H., Nije, V., Bierria, T., Detlefsen E., Steinman, R.A. (2004). Internet usage by low-literacy adults seeking health information: an observational analysis. *Journal of Medical Internet Research*. Vol. 6. Online available. <http://www.jmir.org/2004/3/e25/> (2.07.2006).

(74) Doupi, P. (2005) Personalized Patient Education and the Internet: Linking health information to the Electronic Patient Record. STEPPS in burn care. STAKES Research Report 152. 193 pp. Finland.

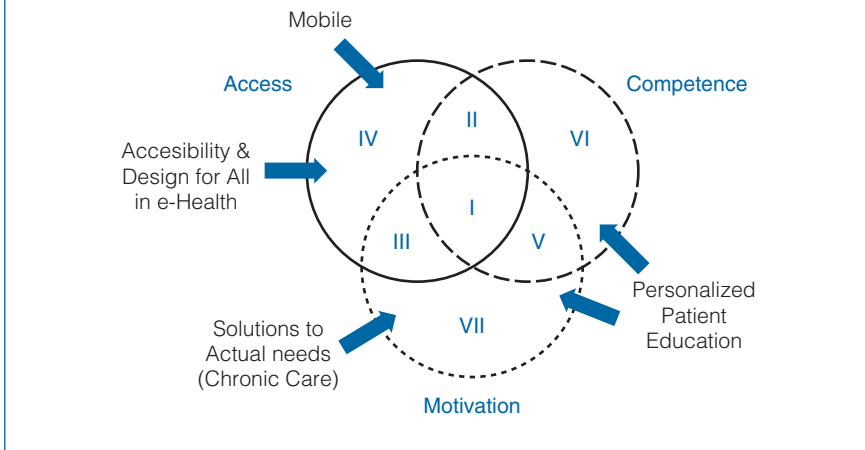
increase. There is an objective need of tools supporting new models of chronic care and the integration with services for the elderly. In fact, i2010 pointed it as a priority action to demonstrate the potentialities of information society for the citizens in Europe. It is also linked to the lines of action addressed by FP VII and other big initiatives at European level as AAL169. However, care must be taken on approaches driven merely from technology. The patient empowerment vision requires a systemic approach. Efforts are needed on modelling processes, systems integration, interoperability, cooperative environments, security, reliability and change management. For example, eChronic Care systems involve the integration of a wide variety of patient empowerment tools regarding communication, health messaging, information access, patient education, ePHR implementation, decision aids, e-appointment and e-prescribing. In many aspects these eHealth personal care systems (currently being developed mostly for chronic patients) are providing the anticipatory vision of the next generation of eHealth infrastructures for the health systems in the future.

Table 7.2. Strategic framework for the development of eHealth Patient Empowerment

Improving factors	Action line	Recommended actions
Accessibility	Promote access to electronic data communication networks	Use of mobile communications Developments based on Aml
	Increase accessibility for all persons	Design for all
Competence	Patient Literacy	Personalized patient education based on ePHR
Motivation	Provide solution to major patient actual needs	Personal mobile eChronic Care

Fig shows graphically the interaction of the proposed strategic lines to improve the adoption of eHealth applications for patient empowerment. It must be noted that Personalized Patient Education would act on «Competence» but also in «Motivation».

Fig. 7.2. Diagram showing the proposed áreas for action, and the factors aimed to be improved



7.5. Focusing action for different population groups

Certain groups will need to be more intensively supported if they are to become active participants in their healthcare. The recommended actions can be focused to match the characteristics of each of the eight types of potential users. Table below maps strategic action lines versus different population characteristics. For example, the consumers «Type I» have the three factors: «access», «competence» and «motivation» to use eHealth applications. This type of consumers is increasing in all european countries and, in long term, it is expected that hopefully the big majority of the europeans will be included in this group.

Focusing in this type of consumers, the recommended line of action is to improve current «offer» of eHealth services and tools by upgrading current systems or by developing new ones. It present opportunities for innovation on areas such as mobile eHealth, ePHR, educational tools, decision aids and eChronicCare. On the other hand it requires active implementation plans by National/Regional Health Services.

Table 7.3. Resumed view of the Strategic action, the patient empowering mechanisms and the type of eHealth tools identified for acting on each of the 8 targeted populations according with the ACM model

Targeted population	Strategic action	Patient Empowering mechanism	eHealth Application
I: ACM	Increase offer of services	Communication Personalized Information Patient education. Health literacy Chronic Care	mHealth ePHR Educational tools eChronicCare
II: ACm	Increase motivation	Patient education. Health literacy Chronic care	Educational tools eChronicCare
III: AcM	Increase competence	Design for all. Accessability Patient education. e-literacy	Educational tools Inclusive eHealth
IV: aCM	Increase access	Applications using Mobile terminals Accessability	mHealth Inclusive eHealth
V: Acm	Increase eSkills + motivation	Patient Education. e-literacy Chronic care	Educational tools eChronicCare
VI: aCm	Increase accessibility + motivation	Mobile Accessability Patient education. Health literacy Chronic care	mHealth eChronicCare Educational tools Inclusive eHealth
VII: acM	Increase accessibility + eSkills	Mobile Accessability Patient Education. e-literacy	mHealth Inclusive eHealth Educational tools
VIII: acm	Increase access + eSkills + motivation	Mobile Accessability Patient education. Health & e-literacy Chronic care	mHealth Inclusive eHealth Educational tools eChronic Care

Looking to the other extreme of consumers class (Type VIII), it refers to populations that have no access, no competence and no motivation. This group is more likely detected among older people, people living in rural areas, immigrants and those with low incomes, specially women. However, as discussed previously, «accessibility» depends not only on having PC and network connectivity but also on e-skills and the usability of the applications. It is basic to consider accessibility for all, avoiding barriers for people with special needs (e-Inclusion).

Often, the barriers for overcoming the lack of access and competence are rooted on the lack of motivation. It has been reported the key role of physicians to promote the use of the new technologies but also the resistance they can represent. This is a key issue as discussed in previous Section 6.

Regarding patients, it is expected that increasing the offer of eChronic Care systems can increase the interest of growing population groups (aged people) that are demanding for more appropriate long term health services. In addition policies for improving healthy lifestyles of citizens (smoke cessation, weight control, etc.) are generating a demand of supporting tools.

7.6. Conclusions

This study covers the eHealth based systems and tools serving for the empowerment of health consumers: citizens, patients and their families and caregivers. Along this report it has been the opportunity to know about the actual situation and the major trends of practical implementations in EU countries. The collected cases offers references on best practices aiming to improve access and quality of care by supporting a variety of patient empowering eHealth implementation approaches.

While there is diversity across European countries there are common themes in eHealth implementations concerning patient empowerment, just as there are common challenges to afford. A shared aspect is the gap between high level declarations and the practical extended adoption of the eHealth tools.

The generalized optimistic expectatives expressed a decade ago about the development of Internet based applications in Medicine (eHealth) have evolved last years to a more realistic scenario, where the national/regional plans for eHealth are the main actors in Europe. At the same time, the vision of of eHealth applications for patient empowering have extended their range from a first wave of quite simple Internet based tools till complex collaborative systems to support chronic care. The current trends

show opportunities for RDT and innovation to reinforce eHealth market with new products and solutions addressing European society demand.

The implementation of eHealth applications serving patient empowerment philosophy presents particular requirements further than the traditional eHealth ones. The understanding of requirements, design principles and implementation issues, concerning such applications, are quite limited. Progress in the field should benefit of future studies which both help to develop theoretical models of patient empowerment, articulate the conditions under which patient empowerment occurs and the eHealth tools role. Interdisciplinary research is needed, not only to explore the technological requirements, but also to address the formal analysis and modeling of care processes, interoperability of different health information systems, organizational barriers, deployment strategies and consequences of creating collaborative healthcare information systems.

The analysis performed using the ACM reference model allows to focus the potential future actions matching the specific needs of different population groups. Conversely, proposed action lines take into consideration the different profiles of targeted consumers, thus articulating efforts for maximizing efficiency.

The proposed lines of action are intended to improve the three axes (Access, Competence and Motivation). The strategy is aligned with current EC policy, i.e. Mobile technologies; Ambient Intelligence (AmI); Chronic Care and e-Inclusion.

The results of the study on the ICT tools for Patient Empowerment offers a base for further analysis and open new views on opportunities for cooperation on eHealth in the EU.

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Annex 1

List of identified types of eHealth applications and tools for patient empowerment

Classification of eHealth applications and tools for patient empowerment			
Categorie/ eHealth Application Layer	eHealth Application Layer	Description	Example
L0: Electronic information production and knowledge management	L0.1: citizens web publishing	information technology based services to support electronic publishing and production of information, educational materials, patient decision aids, etc.	The Almere Health Portal (NL)
L1: Telephonic communication	L1.1: Health Call Center	Systems providing phone advice and information services	NHS Direct (UK)
L2: Data communication	L2.1: Patient-Physician e-mail	Systems based on e-mail to facilitate direct communication of patients with their physicians	WELLCOM (Finland)
	L2.2: SMS health messaging	uses automated SMS messaging to contact citizens for remaining appointments, vaccination advice, blood donors call, etc.	SonLlatzer Hospital (Spain)
	L2.3: Health portal/Web site (Patient oriented)	Portal/web site supporting health information for citizens.	EU Health Portal (EC DG Sanco)

Classification of eHealth applications and tools for patient empowerment (cont.)

Kategorie/ eHealth Application Layer	eHealth Application Layer	Description	Example
L2.4: Health Portal (Administrative and services management)	<p>Portal/web site supporting health administrative information, i.e. Apply online for a European Health Insurance Card, Register online to become a potential blood donor; Apply online to attend a health preventive programme; information on services provided in case of emergency and access channels to them.</p> <p>They can enable a citizen to obtain obtain key information on Hospitals such as mortality rates, complaints, details of available medical specialities and specialists, details of waiting lists and information on individual hospital performance.</p>	Free Hospital Choice (Norway)	
L2.5 Web sites including health interactive services	<p>Web sites which offer interactive services for diagnosis and rehabilitation, health information for self-care, online training.</p> <p>The users have the possibility to do online consultations and participate in videoconferences through the site</p>	<p>Telewelfare.com, Poland</p>	
L2.6 Tools for Patients' virtual communities	<p>Web sites supporting patient communities, self-help groups, etc.</p>	<p>INKA - Informationsnetz für Krebspatienten und ihre Angehörigen (Germany)</p>	
L2.7 Mobile ICT data systems	<p>Staff/Patient Communication e-Home Healthcare</p>	<p>North Calote project</p>	

Classification of eHealth applications and tools for patient empowerment (cont.)

Category/ eHealth Application Layer	eHealth Application Layer	Description	Example
L3:ICT Healthcare Management	L3.1 Personal Health Records	eHealth application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.	Medibank -Hospital de Madrid Group (Spain)
	L3.2 e-Prescribing	eHealth application helping patients to obtain prescriptions and medicines. Avoid repetitive visits to doctor for chronic patients and increase security	Receta XXI – Andalusian Health Service (Spain)
	L3.3 e-Appointment	Facilitates patient management of appointments with doctors. Reminds patients of imminent appointments, giving them the option to reschedule if necessary.	
L4. Personal Health Platforms	L4.1 Self-care tools	Tools allowing patients and health care professionals to collaborate in the development of self-management plans that integrate the clinical expertise of health care professionals with the concerns, priorities and resources of the patient. This type of applications help patients to take control of their condition, providing good information services - at the right time and in the right form. This include well-validated references and websites for further information, and translation facilities, where appropriate. It provides advice and support on how to use the information to make fully informed decisions about their care. They can be connected to Patient-held records.	

Classification of eHealth applications and tools for patient empowerment (cont.)			
Category/ eHealth Application Layer	eHealth Application Layer	Description	Example
	L4.2 e-Chronic care	<p>It refers to ICT systems designed to support communication and coordination among the heterogeneous network of actors involved in chronic disease management.</p> <p>The use of mobile communications allows ubiquitous service provision.</p> <p>They integrates tools to support also physician by providing alerts and decision aids.</p> <p>Patients can receive updated information, educational programmes, and decision aids.</p>	

Annex 2

The Table displays the types of eHealth systems versus the patient empowerment mechanisms

eHealth tools vs. Patient empowerment		Patient Empowering mechanism											
		Communication with health agents	Information Access	Health Literacy	Patient Communities	Decision Aid	Free-Choice	Self-care	Chronic Care				
Types of eHealth systems			√*										
L0.1 Patient Web publishing		√	√*	√	√							√	√
L1.1 Call Center		√*	√	√	√	√	√	√	√	√	√	√	√
L2.1 e-mail		√*	√	√	√	√	√	√	√	√	√	√	√
L2.2 SMS		√*	√	√	√	√	√	√	√	√	√	√	√
L2.3 Web Administrative Services		√	√*	√	√	√	√	√	√	√	√	√	√
L2.4 Health Portal		√	√*	√*	√	√	√	√	√	√	√	√	√
L2.5 Web interactive health services		√*	√*	√	√	√*	√*	√*	√*	√*	√*	√*	√*
L2.6 Tools for virtual communities		√	√	√*	√*	√*	√*	√*	√*	√*	√*	√*	√*
L2.7 Mobile ICT data systems		√*	√	√	√	√	√	√	√	√	√	√	√
L3.1 EPR		√	√	√	√	√	√	√	√	√*	√*	√	√
L3.2 e-prescribing		√	√	√	√	√	√	√	√	√*	√*	√	√
L3.3 e-appointment		√	√	√	√	√	√	√	√	√*	√*	√	√
L4.1 Self-care Management Tools		√	√	√	√	√	√	√	√	√	√	√*	√
L4.2 e-Chronic Care Platform		√	√	√	√	√	√	√	√	√	√	√	√*

√ = used for; √* = most used for (main targeted application).

Annex 3

EC Funded Projects related with eHealth Patient Empowerment	
ARTEMIS	Platform that integrates existing web services concerning eHealth through a semantic framework to link documents and other applications that are already present on the web.
C-CARE	Database of patient-related information accessible to authorised users
CHARM	Telematic services for citizens
CHRONIC	Homecare assistance provided by doctors and healthcare personnel to chronic patients
CHS	Personal health system that can be accessible from home
H-LIFE	Personal health assistant that provides citizens with healthy lifestyle information
eHealth TRENDS	«WHO/ European survey on eHealth consumer trends». Seven countries participate in the project.
IS4ALL	The project will develop a comprehensive code of practice on how to advance the notion of Universal Design, especially in the field of Health Telematics
M2DM	Service care to residential and mobile diabetic patients through a multi-access server that will provide both patients and health care providers with access to telemedicine and information services
MEDITRAV	Medical information for European citizens, especially those with chronic diseases that can be accessible through a smartcard at any European country
PEHR eTen	Personal Electronic Health Record
PIPS	Platform that will help healthcare professionals access updated medical knowledge and the European citizens to choose healthier lifestyles
MOBIHEALTH	Mobile based platform to support chronic care
USABILITYNET	Creation of a web site of best practice examples and resources from relevant projects on usability issues
USE-ME.GOV	Open platform for mobile government services that support usability, interoperability, openness and satisfy the requirements of citizens and public service providers
WEIGHT-INFO	Provision of an integrated environment accessible from all locations that presents issues regarding weight
WRAPIN	Set up a semiautomatic editorial policy service, as an extension of the current Health on the Net Foundation services, using the HON Code.

Annex 4

List of eHealth implementations for Patient Empowerment in EU countries

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Information Production	The Almere Health Portal	NL	Provides a comprehensive self-service programme, through which each citizen can develop his or her own personal health page, using information technology-based services to enhance the personal and individual touch.	
Telephonic Service Call Centre	Dr. Info	Hungary	It is an internet and call centre based service providing health care information for citizens. The service includes information on: availability of health care services (in and out-patient institutions, pharmacies, addresses, opening hours, doctors on duty); information about medicines; general information about structure, availability and function of different health care providers; a phone number collection of different aid organizations; popular medical electronic books about illnesses and home-care. http://www.drinfo.eum.hu/drinfo/	Ministry of Health of Hungary
Telephonic Service Call Center	SAS Responde	Spain	Gives general information and advice by phone.	Regional Health Authority of Andalusia
Telephonic Service Call Center	NHS Direct	UK	The NHS Direct Telephone Service gives advice and support on self-treatment, or if further help is deemed necessary, callers are directed to or connected with the right service.	NHS
Telephonic service	The ChildcareLink	UK	The ChildcareLink service comprises the ChildcareLink web site, a national information line 08000 96 02 96, and details of local Children's Information Services (CIS). The CISs provide face-to-face or phone advice on all aspects of childcare. http://www.childcarelink.gov.uk/deliverychannels/	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
SMS	Blood Donor Booking System	Norway	Uses automated SMS messaging to contact donors for donation appointments and can also call up donors when a particular blood group is urgently required. http://www.shdir.no	
SMS	Appointment confirmation	Spain	Uses SMS to remind patients of imminent appointments.	SonLiatzer Hospital (Spain)
Health Portal Administrative Information	The National Health Insurance Fund of Bulgaria Portal	Bulgaria	Give vital information about the legal aspects of healthcare, as well as names and addresses of doctors, specialist healthcare providers and pharmacies. http://www.nhif.bg	
Health Portal Administrative Information	«Vivere in Salute», Official Government Portal	Italy	A dedicated section on health, «Vivere in Salute» from the official government portal. It provides access to information and services on general health issues. Also offers the opportunity to get in touch with: the Local Health Authority –LHA— through links to the Health Ministry and to Regional portals that help find LHA; health services provided by family doctors; services provided in case of emergency and access channels to them; services provided in each Italian region, featuring links to Regional Health Portals; regions and municipalities that provide the opportunity to book health services online (at the moment, only available in the case of Lazio Region). http://www.italia.gov.it	Government

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health portal Administrative Information Health Literacy	The Paediatric Health Portal	Italy	Website which focuses entirely on children and infants. In addition to providing information also brings a range of services available from a centre of paediatric excellence to the reach of parents in the regions of Basilicata, Calabria, Molise, the Comune di Roma and some other local health institutions and hospitals. http://www.ospedalebambinogesu.it	
Health Portal Information Administrative	e-Health Portal	Malta	Web portal with several e-Health Services as: Apply online for a European Health Insurance Card (E111 Card) as a trans European health coverage for Maltese citizens travelling inside the European Economic Area (EEA); Register online to become a potential blood donor; Apply online to attend a weight reduction programme; global growing concern; Apply online to attend a sexual and reproductive health counselling session organised by the Health Promotion Department; Request online information and advice from the Genito Urinary Clinic Doctor on sexually transmitted diseases, HIV or related issues; Book an appointment online (both doctor and / or citizen) at any of the Out-Patient Clinics within the General Hospital; Register online receive automatic notification/reminders for child immunisation vaccinations and international travel immunisations via sms and/or e-mail, triggered off at birth registration and / or included as an additional service applicable on request; Access a patient electronic library or self-help guide that contains clinically-ascertained information on a variety of medical conditions; Access information on licensed pharmacies in Malta and Gozo. http://www.ehealth.gov.mt/	Ministry of Health, the Elderly and Community Care

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Information	Zorgloket Eindhoven	NL	One-stop-virtual help if you have questions about health, care and well-being in the city of Eindhoven.	
Health Portal Administrative Information Free Choice Hospital Aid	Free Hospital Choice Norway	Norway	Is a website developed by the Norwegian Government which allows patients to choose the hospital in which they want to be treated. It provides full details of available medical specialities and specialists, details of waiting lists and information on individual hospital performance. (http://www.sykehusvalg.net)	
Administrative Information	National Insurance Card System	Slovenia	Website for citizens with complete information and applications about the Slovenian Insurance Card System based on the network of databases maintained by the Health Insurance Institute of Slovenia. http://www.zzzs.si/kzz/ang/hic_indx.htm	Health Insurance Institute of Slovenia
Information Legal issues	The Spanish Patient's Forum	Spain	Listing patients' rights and ensuring them through a number of defined objectives. http://www.webpacientes.org	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal Information Administrative Health portal + Phone Call Center	The ChildcareLink Service	UK	The ChildcareLink national website provides childcare and early years information collected from over 170 English and Scottish local authorities, with sign-posting information from the Welsh National Assembly. The website helps you find useful information about the different types of childcare and early education in your local area and helps you to make the right choice for the whole family. The site also contains details of your local Children's Information Service, who can provide additional help and advice with all aspects of childcare and early launched the ChildcareLink helpline and website in December 1999 as part of the National Childcare Strategy. This strategy aims to help people back into the workplace by removing the childcare barrier. The ChildcareLink service is funded by the Department for Education and Skills and the Scottish Executive.	The ChildcareLink service comprises the ChildcareLink web site, a national information line 08000 96 02 96, and details of local Children's Information Services (CIS). The CISs provide face-to-face or phone advice on all aspects of childcare. http://www.childcarelink.gov.uk/deliverychannels/

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal Information Administrative	Dr Foster	UK	Enable a citizen to type in the name of any hospital or consultant and obtain key information such as procedure waiting times, mortality rates, and complaints. http://www.drfooster.co.uk	
Health Portal General	Ministry of Health	Austria	The Austrian Ministry of Health runs a website with broad variety of themes related to health for citizens. http://www.bmgf.gv.at/cms/site/	Austrian Ministry of Health
Health Portal Information Medical Pharmaceutical Health promotion	Virtual health centre	Czech Republic	Ordinace.cz is a medical portal that provides reliable information on medical and pharmaceutical topics, and on health promotion.	
Health portal	Sundhed.dk	Denmark	The Danish public health portal Sundhed.dk is one of the major elements in the national Danish eGovernment and eHealth strategy. The aim has been to create a common framework of entrance to Danish healthcare with the intention of co-ordinating healthcare service provision, in such a way that everyone has secure access to common information and services across a decentralised healthcare system.	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal General Information	The Citizen's Portal	Portugal	An information web portal for citizens including an important health information for them. http://www.portaldocidadao.pt	All Portuguese Ministries.
Health Portal General Information	Andalusian Health Department Web site	Spain	A complete web with lot of useful updated health-related information both citizens and health professionals. http://www.juntadeandalucia.es/salud/	Health department. Andalusian Region
Health Portal General Information	Portal Health Ministry	Spain	Health portal including information on health. www.msc.es	Government
Health Portal General Information	Portal Salut	Spain	A web site which information for citizens about health topics launch for the Balears Islands Region. http://portalsalut.caib.es	Balears Islands Government
Health Portal	Swedish Medical Center	Sweden	http://www.swedish.org/default.cfm	
Health Portal	NHS Direct Online	UK	NHS Direct Online is a website that provides high quality health information, and is supported by a 24-hour phone-based advice and information helpline staffed by nurses, which offers quick access to health care advice.	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health portal Information Support patient/ doctor relationships	Lasanté	Belgium	Lasanté is the most visited health information web portal in French speaking Belgium. Its aim is to present information on health and illness prevention, and support the relationship between doctor and patient. It provides medical and scientific news and articles in Belgium and worldwide, and an extensive list of the most common ailments for adults and children. www.lasante.be	
Interactive on-line tools +SMS Health Information Medical Advice SMS Administrative information	WELLCOM	Finland	eHealth Services for Turku Citizens 2004-2006 Turku Health Care Department. Use of the internet and related technologies including short message service (SMS). The services enable a client to book an appointment electronically, to ask electronically the health professional about one's health issues, to get an electronic message from the health professional, online forms and health messages (SMS). The services are personal and require user authentication before using the service. User authentication is done by the TUPAS service or by electronic ID cards offered by the Population Register Centre. The service units participating are the Kirkkotiie small district health centre (e.g., GP's and nurse's consulting hours), the contraception clinic, part of the Occupational Health, Turku and part of public students' health care. The number of potential clients who can test the new services is about 25 000.	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal Information Health Advice		Finland	Addiction. http://www.paihdelinkki.fi	
Administrative Information Advice	Health Portal North Rhine-Westphalia	Germany	Provide high-quality information on health-related issues to citizens of the region. Furthermore, typical user enquiries, such as searches for providers of certain treatments or questions concerning consultation are being answered. http://www.gesundheit.nrw.de/	
Health Portal Interactive Services Health Advice	Web4health	Germany (Greece, Sweden, Italy, DK, NL)	German consortium in partnership with partners from five other European countries (Greece, Sweden, Italy, Denmark, the Netherlands) produced a site focusing on mental health and well-being. This is a multilingual website available in five languages which allows citizens to put questions to psychiatric and psychotherapeutic experts, and receive replies directly at their personal email addresses. http://www.web4health.info	Trans-national
Health portal Interactive on-line tools +SMS+ Telephone	Vhi Healthcare online	Ireland	Vhi Healthcare's overall eHealth strategy is focused on meeting customer/user demands for health and lifestyle information, and on increasing contact with its customers. This strategy has led to the setting up of the portal service. It is effectively an electronic gateway to a library of health and lifestyle articles, an a-z of medical matters and health headlines, but it also promotes and increases the interactivity with its customers through ask-the-experts advice, a range of interactive online tools, SMS messaging and a monthly-personalised e-mail newsletter. In addition to this, Vhi subscribers can benefit from a 24/7 telephone line operated by health professionals (a team of nurses), www.vhi.ie	
Health Information HealthLiteracy Medical Advice				

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal Information access Advice Second opinion	Salute e Medicina Internet	Italy	An information web site for Citizens with a lot of useful information about health care. They can obtain a second opinion about the diagnosis given by their doctor. Practitioners and specialists have the opportunity to contribute to the website after a registration procedure whereby they need to provide the website with a copy of their certificate of the Order of Doctors. Once registered, they can access incoming requests for second opinions, and send replies to the questions in their field of expertise. Replies will be made available online. http://www.dica33.it/	
Health portal Medical consultation	Dokter	NL	This is a website that offers medical consultations over the internet with expertly qualified doctors, in a range of clinical specialities. www.dokter.nl http://www.doctor.nl	
Health Portal Interactive Advice	Telewelfare.com	Poland	Telewelfare.com is a telemedical portal offering an interactive service for diagnosis and rehabilitation of the senses responsible for communication (i.e. sight, speech and sound). www.telezdrowie.pl	
Health Portal Health advice	Zdrowie.onet	Poland	Web site where patients can find specialist help on specific issues related to healthy living or health. http://zdrowie.onet.pl/	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal Web Interactive Services On-line consultation Videconference	International Centre of Hearing and Speech	Poland	The users have the possibility to do online consultations and participate in videoconferences through this site. http://www.mcsm.pl	
Health Portal Medical Advice Information Access Training	Polish Internet Clinic	Poland	Web site which offers general health information and the possibility to ask a doctor, take part in online training or a test. It also offers an Internet service for general practitioners. http://www.przychodnia.pl/	
Health portal	Netmed-público	Portugal	(Management and Delivery of Health Services via Internet) - started from an inventory of problems that doctors and the public in general are facing. It consists of a product designed for doctors (www.netmedico.pt) and a part designed for patients Netmed-público. www.Netmed-publico.pt	Netsaúde, s.a. - Gestão e Prestação de Serviços na Área da Saúde via Internet, s.a.
Health portal Web based communication Advice services Information Health Literacy	Vacunation	Spain	Asociación española de vacunología. www.todosvacunados.com	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Health Portal Medical advice Second opinion	Portal de Salud	Spain	A web site where citizens can obtain a second opinion about the diagnosis given by their doctor and health-related questions. http://www.santanderciudadiviva.com/salud/	Health department. Santander City Council. Cantabria Region
Health Portal Self-assessment Interactive services	European Network for Workplace Health Promotion		Offers self-assessment questionnaires to improve workplace health. http://www.enwhp.org	Occupational Health
Virtual Community	INKA-Informationsnetz für Krebspatienten und ihre Angehörigen	Germany	Self-help group of cancer patients. http://www.inkanet.de/	
Virtual Communities	Europe Against Drugs	Ireland	Concerned citizens working together to reduce demand for illegal drugs in line with UN Conventions on Narcotics whilst combining family support and treatment.	Dublin
Virtual Community/ Self-care Management/	Diabetes Juvenil	Spain	Information about Diabetes and for the patients: training, self-care, news, documentation and the possibility of getting an Online Control Programme of glycaemia. http://www.diabetesjuvenil.com/	
Virtual Community Online forum Health Literacy	Parent support project Bletchley	UK	The provision of an online forum for parents and carers to discuss emotional and other issues connected with having a gifted child.	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Mobile ICT Staff/Patient Communication e-Home Healthcare	North Calote project	Finland, Norway Sweden	Patient empowerment was one of the main objectives of the e-Home Health Care at North Calote Project (2003-2006), which was organized as coordinated trials in 5 municipalities of N. Finland, N. Norway and N. Sweden. The project aimed at increased quality and precision of client information handling in home care by introducing mobile ICT equipment to the professional health workers. The data equipment allowed uploading as well as downloading of individual client information together with the patients. A change in professionals' client information handling was expected as a consequence of new tool application, along with a modification of staff/staff as well as staff/patient communication patterns.	
PHR	IZIP	Czech Republic	Web based electronic health record National EHR accessed by health professionals as well as patients. Currently there are 1.000.000 registered users. http://www.izip.cz/	
PHR	DMP project	France	The plan for the development and deployment of an electronic patient record (dossier médical personnel - personal health record) for all French nationals was formally initiated by a law passed by the French government on 13 August 2004 for a major national reform to healthcare provision. The DMP will cover multiple health care sector. Enabling health professionals to access patient care records electronically from any location. http://www.d-m-p.org/index.php	Ministry of Health of France

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
PHR	Akteonline	Germany	The aim of this project was to design and develop a personal electronic health record (EHR) in order to support patient empowerment and additionally to enhance their communication and information exchange with health professionals through this EHR.	University Hospital Muenster
PHR	LifeSensor	Germany	Web-based personal health record allows patient electronically manage, control, and coordinate lifelong health information in one convenient and secure location. Other health team members whom patient authorize can also access, update or add information when they need it from any location. It is sub-divided into three modules: administrative data, basic medical data and disease or lifestyle related assistants (e.g. regarding diabetes or fitness). www.icw-global.com www.LifeSensor.com	InterComponent Ware AG
PHR Web-based health records communication messaging	HealthlinkOnline	Ireland	National Healthlink project is a web-based messaging service, which allows the secure transfer of patient information over the internet. The message types available in the HealthlinkOnline system are: laboratory results, radiology results, death notifications, discharge notifications, discharge summaries, A & E attendance notification, waiting list updates. http://www.healthlink.ie/	Health Service Executive

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
PHR	MediBANK	Spain	System for storage of personal clinical information accessible from Internet. It incorporates services of medical data digitalization; support to emergencies, health agenda and clinical evolution follow up. It uses a health smart card system for patients identification and security. http://www.medibank.es	Grupo Hospital de Madrid
PHR	SUSTAINS (Support Users to Access Information and Services)	Sweden	Creates «a copy of Internet banking but for health care.» Users have health care accounts and log in using a one-time password (that is sent to their mobile phone three seconds after the PIN code is entered) to ensure privacy while personal information is being transferred both ways. Users can explore their medical record in detail and view a list of prescriptions and lab results. They can also exchange information with their physicians.	(Eklund & Joustra-Enquist, 2004).
PHR	Global Health ID	UK	EMMS International offers Global Health ID, a service that enables individuals to maintain personal health records via the Internet and provides a membership card that alerts potential health care providers of the availability of the information in an emergency. http://www.pemms.com/solution?c29sSUQ9MJU	EMMS International (UK)

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
PHR	PAERS	UK	The PAERS (patient access to their electronic record) System, being tested at four GP offices, allows a patient to access his or her EHR via kiosks at the office. Its notable feature is the use of thumbprints in lieu of passwords.	NHS London, 2003; «Thumbprints used to access patient records.» 2004.
PHR	Renal PatientView	UK	Provide patients with online information about diagnosis, treatment, and latest test results. http://www.renalpatientview.org	Renal Information Exchange Group (RIXG)
PHR	Babylink	UK	Give parents access through the internet to clinical information about their baby and to link this intelligently to unit guidelines and to a clinical knowledge database. The idea is to ensure that parents get information that is relevant to the specific problems of their baby. The system would also be used to improve discharge planning with parental and community involvement. The project will incorporate the diaries and so maintain the «informality» of this means of communication. The families will have access not only over the internet but also at the cotside and at a dedicated terminal within the unit (in a quiet place outside the nursery). They will be able to post messages and questions which they feel have not been dealt with by the staff while they were visiting their baby. Sometimes parents may feel it is easier to ask a question on line rather than face to face. Parents will be able to control who has access to their baby's information by user defined passwords that they can change at anytime. www.babylink.info/Edinburgh/BabyLink/project.aspx ;	Scotland

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
PHR	HealthSpace	UK	HealthSpace as an online personal health organiser providing an integrated, secure patient portal into NPfIT services through a simple, user-friendly interface. Patients will be able to electronically access health records via HealthSpace a secure, customisable web space for storing and accessing personal information. http://www.healthspace.nhs.uk	The National Programme for IT (NPfIT): NHS Connecting for Health
e-Appointment	Patient Care Messaging	UK	Reminds patients of imminent appointments, giving them the option to reschedule if necessary. http://pcm.iplato.net/nhs1	
e-Prescribing	Receta XXI	Spain	Save visits of chronic patients to physicians for repetitive prescriptions. http://www.juntadeandalucia.es	Regional Health Authority
e-Prescribing	Apoteket	Sweden	The application enables prescriptions to be sent to either a specific pharmacy or to a prescription mailbox. Currently, 50% of all prescriptions in Sweden are transferred electronically.	
Self care Health portal Health Literacy	Plan Cancer	France	The National health priority on cancer prevention. http://www.plancancer.fr/	National Institute of Cancer
Self care tools Web based services Information Education Home telecare	Home Rehabilitation Clinic	Poland	Offers a programme of learning, therapy and rehabilitation targeting children with hearing impairments and communication disorders. http://www.ifps.org.pl	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
Self care Health Literacy	Respira	Spain	Information on Asthma for parents and public. http://www.respirar.org/eng/infoparents/index.htm	
Self care Health Literacy	Espalda	Spain	Information on back pain management. www.espalda.org	
Self-care tools	Pure Quality Life	Sweden	Provides neurocognitive exercises aimed at decreasing stress. http://www.pql.se	
e-Chronic Care	VEDIAB	Austria	Service, which allows diabetic patients to submit glucose readings by SMS and to receive physician feedback via the same method. http://www.ai.univie.ac.at/oefai/kbs/diabetes.html	
e-Chronic Care	DiasNet	Denmark	The DiasNet system is based on a well documented decision support system, Dias, designed for use by clinicians. The scope of DiasNet has been widened from being used by clinicians to give advice on insulin dose, to also being used by patients as a tool for education and communication. Patients can experiment with their own data, adjusting insulin doses or meal sizes. In this way different therapeutic and dietary alternatives can be tried out, allowing the patient to gain experience in achieving glycaemic control. DiasNet is implemented in JAVA according to the client/server principle, enabling a new way of communication between patient and clinician: in case of any problems, the patient simply phones the clinician, who immediately, using his or her office PC, can take a look at the data the patient has entered.	Department of Medical Informatics and Image Analysis, Aalborg University, Fredrik Bajersvej 7 D1, DK-9220, Aalborg, Denmark

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
eChronic Care	Terivan Antico	Finland	To report blood reading from coagulation risk electronically to facilitate accurate and effective use of anti-coagulation medication. http://www.terivan.com/pdf/TerivanAntico.pdf	Terivan Oy Kuninkaankatu 30 FIN-33200 Tampere Finland Y-tunnus 1609790-0 www.terivan.com info@terivan.com
eChronic Care	Terivan Hyperton	Finland	Is a treatment specific ICT solution for hypertension follow-up in primary health care. http://www.terivan.com/pdf/TerivanHyperton.pdf	Kuninkaankatu 30 FIN-33200 Tampere Finland Y-tunnus 1609790-0 www.terivan.com info@terivan.com
e-Chronic Care	Diabcarnet	France	Targets young people with type I diabetes. http://www.diabcarnet.com	
eChronic Care	Caring for Carers	Ireland	http://www.caringforcarers.org	
eChronic Care	Dementia Emilia Romagna	Italy	To support citizens with mental health problems, including dementia. Online Information and Suggestions about Dementia from the Emilia Romagna region of Italy. http://sezionedemenze-emiliaromagnasociale.it/	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
eChronic Care	Long Term Oxygen Tele-Home Monitoring	Italy	Home-based monitoring service for patients suffering from chronic respiratory disease. This system enables comprehensive monitoring, which includes vital signs, heart frequency, oxygen consumption and reserve levels as well as patient compliance. http://www.uiss22.ven.it/pneumologia	
e-Chronic Care	Thrombosis Digital Logbook	NL	Enables chronically ill patients at risk from thrombosis to self-monitor their progress under the remote supervision of their treating doctor, who is always able to intervene. http://www.portavita.nl	
eChronic Care	VieDome	NL	Remote monitoring to enable elderly persons to continue to live in their own homes. Sensors located in their homes can monitor any physical signs which need to be kept under review, and these are monitored by a central medical service or virtual care centre, if necessary a touchscreen monitor links the patient directly to doctors and nurses who give professional advice and decide on any future action. The project has also developed several services which maintain the quality of life for elderly persons, via activities such as shopping and hairdressing. http://www.viedome.nl	

List of eHealth implementations for Patient Empowerment in EU countries (cont.)

eHealth Application Type	Project/Program Title	Country	Short description	Comments
eChronic Care	AIRMED	Spain	AIRMED platform provides support for chronic disease management (cardiac illness, OAT, asthma) based on mobile communications and Internet. It includes patient-physician messaging system, PHR, care guidelines and information resources.	Institute of Health Carlos III
eChronic Care	The Linkcare	Spain	Allows the remote monitoring of oxygen saturation, ECG, spirometry and accelerometry in the home-based treatment of patients with chronic respiratory disease. http://www.linkcare-bcn.org	
eChronic Care	Chronic Disease Management project	UK	It uses the telephone and a personal identification number for chronically ill patients to telephone in with updates on their progress. A carefully pre-defined script allows relevant information to be collected which is then reviewed by doctors who decide whether or not any medical intervention is necessary. http://www.axsys.co.uk/ #north_glasgow	

Annex 5

Frequency of eHealth applications for Patient Empowerment in EU countries (collected sample n=80)					
Categories/ eHealth Application Layer	eHealth Application Type	Number by type	Relative %	Comments	
L0: Multimedia production (1)	L0.1 Health information production	1	01.25	Patients Web publishing	
L1: Telephonic communication (4)	L1.1 Telephonic based Service. Health Call Center	4	05.00	Evolving to integrate with Health Portal	
L2: Data communication (42)	L2.1 Patient-Physician e-mail	0*	00.00		
	L2.2 SMS health messaging	2	02.50		
	L2.3 Web based Administrative Information and services	10	12.50		
	L2.4 (Patient oriented) General Health portal	9	11.25		
	L2.5 Health Portal with Interactive services	16	20.00	Includes medical advice	
	L2.6 Virtual communities support tools	4	05.00		
	L2.7 Mobile ICT data systems	1	01.25	Driven by mobile development	
L3:ICT Healthcare Management (14)	L3.1 Electronic Personal Health Records (ePHR)	12	15.00		
	L3.2 e-Prescribing	2	02.50		
	L3.3 e-Appointment	1	01.25		
L4. Personal Health Platforms (18)	L4.1 Self-care tools	5	06.25		
	L4.2 e-Chronic care	13	16.25	Active I+D+i. New AmI technologies prospects	
Total		80	100		



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