Valencia
29th & 30th
November 2012

IV Workshop on
Technology for Healthcare and Healthy Lifestyle 2012

Proceedings

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Proceedings

IV Workshop on Technology for Healthcare and Healthy Lifestyle

Valencia, 29th - 30th November 2012

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IV Workshop on Technology for Healthcare and Healthy Lifestyle 2012

Agenda

Valencia, 29th & 30th November 2012

IV Workshop on Technology for Healthcare and Healthy Lifestyle
HA RECIBIDO EL RECONOCIMIENTO DE INTERÉS CIENTÍFICO SANITARIO POR EL MINISTERIO DE SANIDAD, SERVICIOS SOCIALES E IGUALDAD

IV Workshop Technology for Healthcare and Healthy Lifestyle 2012

Thursday, November 29th

11:30 -12: 00	**Welcome and registration**
12:00 - 12:30	**Opening in charge of the Organizing Committee**
	Welcoming to workshop for external participants. Brief presentation of the project objectives.
12:30 - 14:00	**Session I**
	eHealth: Challenges and opportunities **(Chair: Carlos Fernández)**
	Ángela Posada (Universidad CEU Cardenal Herrera, Valencia, Spain) *"Smart Packaging. Interaction and security for a better quality of life"* **Jose Enrique Borrás Morell** (Department of Computer Science, University of Tromsø, Norway) *"Analysis of Hospital YouTube Videos as health reliable sources"* **Johan Gustav Bellika** (Department of Computer Science, University of Tromsø, Norway) *"Ehealth systems and information needs of physicians"*
14:00 - 16:00	Networking lunch
16:00 - 18:00	***Session II***
	eHealth: New Developments and services **(Chair: Vicente Traver)**
	Beni Gómez Zúñiga (PSINET IN3, Universitat Oberta de Catalunya, Barcelona, Spain) *"ePACIBARD: Collective Intelligence for research in ultra rare diseases. A conceptual model"* **Carlos Sánchez Bocanegra** (Department of Computer Science, University of Tromsø, Norway) *"Saluteca, a Spanish Health Video Portal"* **Elena Villalba Mora** (Institute for Prospective Technological Studies. Joint Research Centre, European Commission, Seville, Spain) *"Towards Integrated Personal Health and Care Services deployment in Europe"*

IV Workshop on Technology for Healthcare and Healthy Lifestyle 2012

Agenda

Valencia, 29th & 30th November 2012

GOBIERNO DE ESPAÑA MINISTERIO DE SANIDAD, SERVICIOS SOCIALES E IGUALDAD
IV Workshop on Technology for Healthcare and Healthy Lifestyle
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IV Workshop Technology for Healthcare and Healthy Lifestyle 2012

Friday, November 30th

10:00 -10: 15	**Opening in charge of the Organizing Committee**
10:15 - 11:45	***Round table****
	Alfabetización en salud e Internet
	Chair: Ignacio Basagoiti *(Institute ITACA - Universitat Politècnica de València, Spain)* Serafín Fernández y Antonio Jesús Ramos Morcillo *(Cuidando.es & Cuidando.org)* Carlos Luis Sanchez Bocanegra *(Department of Computer Science, University of Tromsø, Norway)* Manuel Traver *(Salupedia - Institute ITACA - Universitat Politècnica de València)*
11:45 - 12:15	Coffe break
12:15 - 13:45	***Round Table****
	TIC, salud y sanidad
	Chair: Ignacio Basagoiti *(Institute ITACA - Universitat Politècnica de València, Spain)* José Francisco Ávila de Tomás *(Servicio Madrileño de la Salud (SERMAS) y SOMAMFYC – Sociedad Madrileña de Medicina de Familia y Comunitaria – Madrid, Spain)* Francisco José Sánchez Laguna *(Universitat Oberta de Catalunya, Hospital Universitario Virgen del Rocío y Tromsø Telemedicine Laboratory - Sevilla - Spain)* Anton Civit *(Prof. at Universidad de Sevilla - Sevilla - Spain)*
13:45 – 14:00	**Closing ceremony**

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**All the sessions of the Friday, 30th will be in Spanish language*

More info and last agenda updates in http://www.tsb.upv.es/wths2012/events

Valencia
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November 2012

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eHealth:
Challenges and opportunities

Smart packaging. Interaction and security for a better quality of life

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Packaging and current solutions

Currently, it is not conceived a product without packaging. Product is part of what makes its evolution and development go simultaneously. The packaging industry is constantly growing and that is why concern is the continuous improvement in terms of all the attributes that should be a good package, protection, conservation, distribution and communication and user interaction, among the most important.

The package has been a transformative element within modern society has made it no longer necessary to rely on the seasonal, spatial proximity, temporality to consume certain products, become available at any time of the year, in different sizes, types, amounts, from anywhere in the world and tailored to the current sales rate. It also adds value to the product, in addition to fulfilling its basic functions is to protect all kinds of external agents (insects, bacteria, pollution, falls, manipulation), retain their organoleptic properties (taste, color, odor), transport and distribute, and add other functions like communicate and sell, to be environmentally friendly, and every day be safer for the user at the time of use and avoiding counterfeit or adulterated product taking all traceability requirements.

Just as the Internet, the packaging has been one of the great advances of the last century, making part of the rhythm and lifestyle of people today are looking to interact with the product. So innovation is constant and more attributes are added to the current needs chords.

Have emerged, new solutions that enhance quality of life for users.

Packaging at the new century: active, intelligent and safer.

Differences between active and intelligent.

Packaging industry development is growing constantly. Continuous improvement and developments to reach packaging that include best attributes are a daily concern in this field. Among the most important attributes to be taken account in good packaging are ways of protection, conservation, product distribution as well as communication and interaction with the user. Active and intelligent packaging has born to enhance abovementioned attributes increasing their lifetime as the possibility that products can be longer on the market without getting expired. The latter has resulted in greater amount of time for distribution and trading as also less product returns by expiration date. Therefore, packed product offers greater certainty of its quality along its lifetime.

It is important to clarify some packaging concepts. European Union at March 2004 defined an active packaging as that intended to act on the product preserving its quality and conservation.

Likewise, intelligent packaging is one capable to give consumers the information about product status which this contains. Also, some definitions are cited according to some authors who have written on the subject. A package can be described as an asset when it develops some additional function to provide an inert barrier against external conditions (Rooney, 1995).

Hotchkiss defines this as one which interacts directly with the product and/or its environment improving one or more aspects of its quality and safety. Oppositely, this author also discusses on passive packages, those which act as a passive barrier in order to separate the product from environment. Otherwise, active packaging is defined as a food-package-environment system acting in concert to improve the health and quality of packaged food and these increase its useful life (Catalá y Gavara, 2001).

Active packaging focuses on the need to protect and conserve food both mechanical damage during handling and deterioration of this when it experiences different environments during distribution and storage. In turn, intelligent packaging according to Irina and Ariana Vidal Díaz (Universidad Nal. De Quilmes) is defined as the packaging art which contains externally or internally, an indicator to generate an active history of the product and thus determining its quality. These kinds of packages are also called interactive or sometimes are described as functional according to Fernandez, 2000. These use either properties, food components or some packaging property as indicators of track quality. These are mainly time-temperature indicators, microbiological quality indicators, indicators of oxygen or carbon dioxide. Iin this group are the containers bearing labels printed with special inks that are used as indicators of the quality, safety or treatment of packaged product. They are based on physicochemical reactions, enzymatic or other, leading generally to the color change of the device, thus indicating damage or change that took place in the food.

Advantages of active packaging in its various forms:

• Responsiveness of the pack against to internal changes

• Performing as heating, cooling, or fermentation, which can already perform in the same package

• Reducing the use of additives or preservatives and can be incorporated in the same package

• Cost reduction in packaging under modified atmosphere techniques, exercising this control in individual products (previously only was possible in bulk).

Consumer Trends

Consumers are increasingly demanding and convenience is a key user of today and tomorrow will surely also have been major changes in lifestyle that require you to be more practical, the growth of cities, - everything should be faster and reach more places-increasing population, the changing role of women, international trade leads to the need to avoid losses and food waste, concerns about hygiene and consumption natural food, the deterioration of the environment, among others, urging changes in all sectors. This also affects the packaging industry and its constant innovation and application of technologies to respond to new demands and requirements. Many companies saw a little forward are researching and developing alternatives, and there are countries like USA may already have some early results and although the active and intelligent packaging are not yet on the market greatly expanded its future looks promising as possible to offer consumers the convenience, quality and safety they need. This type of packaging can be electrical, electronic, mechanical or chemical allowing them to fulfil one or more functions such as detecting bacteria and interact with them so they do not contaminate or spread, warn when a product is open and damaged its label, determine how long they have on the shelf warning that must be removed, change colour depending on the degree of cold and time taken off its chain, blind and disabled warn of product information and status, warn patients each feeding time and the amount of medication they have for you are not left without it, and many more are making many advantages and have a very high social function as save lives, prevent disorders, crime and theft, forgery , prevent bioterrorism, reduces mortality by cause of food infections, prevent disease, save costs and time.

All these functions will be coordinated systems that give added value to the products and will lead in a few years and massively consumed, an important part of these are the labels that enhance product safety, expedite inventory, monitor supply chains, will lower returns and losses, which will replace the bar codes are the RFID (radio frequency tags), as well as microchips and printed circuits (microelectronics and nanotechnology), digital paper that will have all the information of the product and variety sensors.

All this is in addition to the large range of packaging systems for various materials and features that eventually will change and evolve in order to integrate each other what employers must adapt to keep up and not take risks.

Overall the trend is to the safety and efficient use and clear containers must be safe for the producer-entrepreneur, for the product to the distributor, to the environment and of course to the consumer, then observe containers speak, explaining instructions, which advise when you save the product if this much time off, you have indicators that sparkle and shine, improving interfaces with the consumer by making them clearer, the packaging, as part of the product solves problems of interpretation time to keep, save, read, take and report how that relates to the five senses, any user can easily access and understanding of a product without having to spend extra time to understand. These are the opportunities for active and intelligent packaging allowing the purchasing decision that is increasingly complex and have to be fast because customer loyalty.

Within the company's designers and marketers have a tool that makes your commitment is greater, achieving good growth and meeting all the requirements of the company, the environment, the user and the environment.

Fig. 1 Some cases, such as photos

The cans are recyclable aluminum easy open, the system is heated container containing expanded polystyrene, such as the maintenance mechanism precooked itself, and likewise makes thermal barrier the time to avoid the rapid cooling and heating food, and in order to avoid burns added to the user. Uses heat dissipated in an exothermic reaction reached its peak (90 ° approx.) Within 15 minutes. Begins to dissipate heat after one hour aprox. It is possible by a known chemical reaction between sodium hydroxide and zinc oxide (of course somewhat more water).

Fig. 2 Seals with TTI indicator

Pharmaceutical Sector

Pharmaceutical companies have traditionally shied away from investing heavily in clinical trial packaging, the logic being that many of the drugs tested in clinical trials fail to reach the stage of commercialisation. But changes are afoot. Indeed, in recent years, contractors in the clinical trial services sector, such as Almac and MWV, have witnessed the beginning of a significant change in Big Pharma's attitude.

Rather than simply focusing on cost-cutting wherever possible, many of the large pharmaceutical companies have really started to recognise the benefit of using 'smart'

packaging, which can substantially improve patient compliance, at the clinical trial stage.

Their revised reasoning is that enhancing patient adherence improves the accuracy of clinical trial results, giving drugs a greater chance of eventually being commercialised, therefore ultimately improving the company's revenues.

Analysis of Hospital YouTube Videos as health reliable sources

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Abstract— **Information health retrieval and YouTube can be used as a powerful set of tools aimed to improve user's health knowledge. However, YouTube videos must be carefully analysed in order to avoid misleading health content; such as information not related to health, false medical products promoted by for-profit organizations, or non-up-to-date treatments.**

Knowing where good-quality health videos are is the first step to be able to offer reliable videos to patients. To analyse the relations among comments, views, rating, favourites, etc. can help us to reach this purpose.

Health knowledge can be associated to hospital or medical institutions; through this premise, and helping by YouTube health communities, we have designed and algorithm to find videos from hospital or medical institutions. Helping users to find good-quality health information, in this case through reliable videos, can be a crucial step to help people facing health treatment or screening decisions.

I. INTRODUCTION

Undoubtedly, the Internet is the major source of health information today. Every day the Internet is becoming more important in finding out health information [1, 2]. People use it to obtain health information such as disease symptoms or medical treatments [3, 4], whether reading articles, watching videos or asking in health forums. Alike medical centers, health institutes and associations related to health and patients use the Internet as a means of communicating health information.

However, a major problem with this kind of services is that many websites have inaccurate information, such as commercials, obsolete information, etc. [5] which is not easy to identify. The overwhelming amount of health information available makes it difficult to search good-quality health information on the Internet for the user [6], especially when users are not familiar with new technologies or when their health knowledge is limited [7].

YouTube is the most important video-sharing website on the Internet [8]. Its usage does not stop growing and expanding. Each minute 72 hours of video are uploaded to YouTube and it has nearly 800 million of unique visitors per month [9]. YouTube social media tools allow users and communities to interact, thus they can easily upload and rate videos, post comments, etc. If we can analyze this information in order to rate videos confidence, we may use this to offer reliable videos for users.

YouTube is increasingly being utilized to share health information from Hospitals, associations, government departments to companies and users [10]. Despite its significant success, video sharing platforms have problems when checking their content, mainly because it requires knowing whom the video is aimed at as a previous step to revise its reliability. Up to now, there are few studies within computer science on YouTube for specific domains [11-13], rather than on specific domains, such as health [14].

The problem comes when users have to rely on a misleading video: YouTube ranking is not based on good-quality content. If we are able to retrieve reliable health videos despite of their relevance, or their position in the YouTube ranking, we would offer to the users the correct videos to rely on. Obviously, the issue is to know how to check the video content. A considerable amount of literature has been published on YouTube data analysis, such as studying the relations between video ratings and their comments [11] or focusing on the social networking aspect of YouTube and their social features [12, 13]. Close to our line of investigation, there are studies focused on health communities and video recommendations [15] or in search engines and their results about health searches [16]. But very little was found in the literature regarding the question of the truthfulness on YouTube health videos contents.

Difficulties arise, however, when an attempt is made to implement good-quality video finding algorithms based on YouTube statistics, mainly because videos that appear on the first entries are more likely to be viewed and interacted by users, Yule process or rich-get-richer principle [17]; thus, while the most popular videos have clear metadata: high number of likes, dislikes or comments, non-popular videos metadata used to be poor even though they can be reliable [11]. On the other side, since users and communities share

videos they are no longer independent from each other. These relations can be used to filter misleading health information. At this point, we assume that hospital channel videos health content quality is higher than videos produced by users; and similar process occurs between health organisations, medical centers and users.

This paper suggests a study focusing on YouTube hospital communities, where we take advantage of their YouTube social features available (comments, likes, dislikes); and evaluate YouTube video's metadata. Our approach also implies studying the features related to the uploaders such as their description, videos they have shared, or their favourite videos. Besides, an analysis of the components related to the video such as the number of views per day, total number of likes or dislikes, etc.

II. Material and Methods

This paper studies the YouTube hospitals videos interactions. For this porpoise we used the Health Care Social Media List [1] from Ed. Bennet [18] to obtain YouTube Hospital's channels. Social networking information for 1472 hospitals and health care organisations is included in this list; and below half (628) had YouTube Channel.

We retrieved the top-100 videos on YouTube based on different Diabetes queries. The queries where adopted from a study carried by L. Fernández-Luque [15]. The final sample consisted of 2000 videos from 20 different searches. Doing in that way, using Ed Bennet list, you can compare results but please note that you can use also the list from Observatics[19] although in this case would be in Spanish. Finally, data management and analysis was performed using YouTube API [20] and Visual Studio 2010.

To know how YouTube regulates hospital health videos, a series of operations were performed:

Analysis of the Ed. Bennet Health Care Social Media list Diabetes videos. We want to know how YouTube classifies these hospitals' videos. We selected all the videos uploaded by each user in the Care Social Media list. After that, we selected Diabetes videos as a case of study. We filtered each video searching for the "Diabetes" and "diabetic" terms in their titles and descriptions. Data stored for each video retrieved was: number of views, ratings and when the video was uploaded.

Finding where the authors from the Ed. Bennet Health Care Social Media list are in the YouTube top-100: we retrieved the top-100 YouTube Diabetes videos, searching for Care Social Media list users. The scope was to know where these videos were in the YouTube ranking. We used as a YouTube search query 20 terms related to Diabetes. YouTube configuration parameters where: language English, location worldwide and Safety off.

To compare authors from the YouTube top-20 and the top-100 Diabetes videos. We use 20 Diabetes terms as a search query in YouTube; we compared the authors from the top-20 and the top-100 YouTube videos. We searched which were included in the Care Social Media list users. Note we also searched for users whose description included "hospital" and "medical center" terms.

III. Results

Here, we present the results obtained from the analysis of the Care Social Media list user's videos. We retrieved 1295 videos related to Diabetes from users of the Care Social Media list; where 823 videos were unavailable to be interacted with users[2], while 472 videos allow users comment and rate videos.

Videos where users' interactions were available presented the following characteristics:

- 196 videos had 1 or more comments (15% of the total)
- 68 videos had 1 or more dislikes (0.005% of the total)
- 456 videos had 1 or more likes (35% of the total)

We can observe a low interaction between hospital's users and their videos. A depth analysis of available videos shows that 64 videos had one or more comments (0.05%) and 10 videos were rated with 10 or more likes (0.007%), while there was 1 video rated with more than 10 dislikes (0.0007%).

At the same time, we obtained the top-20 YouTube results for each query, and expanded each search for the top-100 YouTube results. We analysed the video authors seeking for the ones who were included in the Care Social Media list. We found that there were 4 videos in the YouTube top-20 whose authors were in the Social Care List; while in the YouTube top-100 there were 26 videos (4 videos from the top-20 and 22 videos from the top-21 to top-100) whose authors were in the Social Care List.

A new ranking can be done joining the Social Care List authors, who are in the top 100 YouTube results, with the YouTube top-20 results

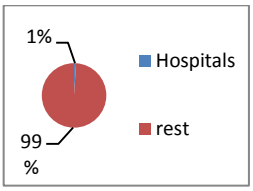

Figure 1 YouTube top-20

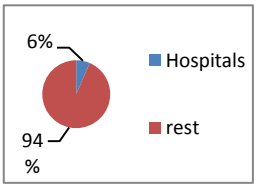

Figure 2: New-Ranking top-20

A comparison between the authors of the new top-20 ranking results (figure 2), and the old top-20 results from YouTube (figure 1) shows that ,while 1% of the authors of the old top-20 results were in the Ed. Bennet list (4 videos); new top-20 ranking had 6.5% of their authors in the Ed. Bennet List (26 videos).

IV. Discussion

Videos from Health Care Social Media list users haven't got enough data to establish any relation between videos and users. The most important limitation lies in the fact that there was a low interaction between hospital's users and their videos. This can be explained because most of Health Care

[1] Data was collected on September 2012

[2] Video's Author can choose to disable comments and rates.

Social Media list videos are not ranked in the first positions by YouTube as we can see in figure 1[17].

Besides, we have inferred that hospitals have good videos, it is an oversimplification. We also need to study it with real users.

If we assume health knowledge comes from hospitals and health institutions, but their videos are not highly ranked in YouTube searches, it will be difficult for the user to find them.

V. Conclusions

The YouTube video sharing platform offers many opportunities to retrieve good-quality health videos. However, to filter misleading videos from the good ones can be a hard and tedious task; especially when users have not medical knowledge. A reasonable approach to tackle this issue could be to design an algorithm that allows users to retrieve reliable health content over relevance health videos. YouTube platform as a social network community is the way we have chosen to reach such objective.

Acknowledgment

We appreciate the important contributions of the TSB-ITACA- Universitat Politècnica de València group for its collaboration in the elaboration of this paper.

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Ehealth systems and information needs of physicians

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***Abstract* — Telemedicine and ehealth systems have not been able to take the final step into large scale usage. This paper provides a hypothesis of why this goal has not been reached, so far. It also outlines the constraints future ehealth systems need to meet and what resources are needed to be in place to build ehealth solutions that may succeed in achieving large scale adoption and use in the health service provision. The paper concludes with a list of recommendations based on the outlined constrains for ehealth systems.**

I. Introduction

Many aspects constrain how ehealth systems for communication between patients and primary care physicians should or could work. The ehealth system must provide information that the physician need when caring for the patient, in an efficient manner at the point of care. Culture and guidelines for computer usage during a patient consultation also influence what usage scenario is possible. The prevalence of the diseases influence which diseases that are suitable for ehealth systems as the volume and use frequency may be important factors in a physicians decision on whether to offer an ehealth service or not. The seriousness of the disease may influence the physicians' willingness to use an ehealth system, for example, no physicians would like to overlook a cancer diagnosis. Also, the type of disease episode influence whether and how ehealth can support a patients´ case. Finally, computer literacy issues influence whether a patient or a physician is willing to use or provide ehealth based services (Sayah et al, 2012) (Nielsen et al, 2004).

II. Background

Ehealth and telemedicine has been envisioned a bright future for a long time. However, the fields have struggled to take the transition into large-scale routine use. One possible reason for this may be the lack of focus on the primary care physician's role as initiator of telemedicine services towards the specialized care service. Another reason may be that telemedicine and ehealth solutions have not been able to meet the demands such services need to fulfil to become large-scale services. These demands are given in national legislation and strategies for development of our health services. Telemedicine and ehealth services should (among a number of other goals) help the patient to prevent, treat or master their health problems, ensure equitable and good quality of the services and meet the needs of the patient in a resource efficient manner. The services should be effective, safe, available, resource efficient, coordinated and provide influence to the patient. As 100% of all patients have to visit the primary care physician (in countries where the general practitioner has a gatekeeper function), before accessing specialist care services, their role as initiator of telemedicine services inside the health system needs more attention. As relatively few primary care physicians have PhD degrees, compared to hospital based physicians, the bias in volume of research performed by both groups is natural. A relevant research question for the future should anyway be: What telemedicine and ehealth services do primary care physicians need? Looking at the most frequent communication partner for primary care physicians, the patient, makes it clear that services towards this group have the largest potential for large scale usage. This imply that ehealth services towards the primary care physician´s patients may need to be addressed before the cases and accompanying documentation are forwarded to the specialist care service through telemedicine or any communication system.

A recent review of symptom based patient – healthcare personnel communication using telemedicine and ehealth tools showed that most studies are performed outside primary care. Only one of the 29 identified studies on communication of symptom information between the patient and physicians were done in a primary care setting (Johansen, Henriksen, et al. 2012; Johansen, Berntsen, et al. 2012). Also, most studies are performed on chronic patients, with long term collaboration needs with health personnel (ibid.). The single study focusing on primary care settings was a web based support for self-care explored management of minor but acute symptoms (Yardley et al. 2010). The health service types identified by the review were *consultation support (7 studies)*, *monitoring with clinician support* (12 studies), *self management with clinician support* (9 studies), and *therapy* (1 study). Most studies focused on a specific diagnosis whereas only one of the studies focused on several.

This paper tries to analyze what constraints need to be satisfied and what resources need to be available to build successful ehealth services that may survive the transition into a large-scale routine use.

III. Method

Identifying ehealth solutions that will survive transition into a large-scale use necessarily need to be found in areas we have not look at before. However, proposing new ideas or

solutions provide no guarantee that these new ones will be successful. Maybe there are no solutions to our problem. The method applied in this paper follows the early stages of a system engineering methodology in a rough way. We try to identify constraints for our solution, perform an analysis using our knowledge and experience, and propose a direction for the development of a solution. Ideally, our research question should be directed towards primary care physicians. In lack of data directly from this source, we have used our experience, based on more than 20 years of experience on developing and deploying telemedicine and ehealth systems in Northern Norway at the Norwegian Centre for Integrated Care and Telemedicine and in Spain at the Valencia region, to deduce the constraints that we hypothesize influence adoption of ehealth services. The validity of our claims and basis for our hypotheses are necessarily weak and need to be explored further. However, history has proved that the transition of services into large-scale use has not been very successful. We therefore need new ideas to guide the development of the future ehealth and telemedicine services. As the constraints presented in this paper are ideas for construction of future systems, they cannot be proved in a scientific manner; neither can our recommendations, at this point in time. Therefore, let us think out of the box to find an answer that up to now has not been found at the typical boxes.

IV. Results – constraints for ehealth system

In the following sections we address each of the issues touched upon in the introduction section.

A. Satisfying information needs

The Information needed by physicians when caring for patients are patient data, population statistics, medical knowledge, logistic information (procedures & guidelines) and social influence (how other doctors treat their patients), as outlined by Gorman (Gorman 1995). Ideally, all these information categories may be provided in an integrated ehealth solution. To establish such ehealth services two important resources need to be available, large amounts of EHR data and EHR system software. The most important one is a system that enables reuse of data and integration of ehealth solutions. Without such access it will be impossible to satisfy all the information needs of the physicians in an integrated and efficient manner. If looking at the five categories from a long timespan perspective, all categories are dependent on access to large amounts of EHR data. Population statistics can be generated directly from available EHR data. For communicable diseases, the timeliness of such data may also be important as input to primary care physicians decisions (Bellika et al. 2007). Current medical knowledge production is to a large extent based on clinical data produced by (randomized controlled) clinical trials. However, comparative effectiveness research based on large collections of clinical data is currently emerging as an alternative source for generation of medical knowledge (Sittig et al. 2012). Logistic information, procedures and guidelines for treatment of patients, is also based on knowledge generated from large amounts of clinical data. The social influence, how other physicians treat their patients, can be generated directly from large collections of clinical data. Patient data, the last category of information that physicians need, is the key to link all the above types of information. To do that, the ehealth systems need to attract the interest of the patients and provide services that the patients need. A large percentage of patients (around 80% of internet users (Andreassen et al. 2007; Gualtieri 2009; Koch-Weser et al. 2010)) currently turn to the internet to locate information relevant for their condition. This information need is the key to attract the patient attention and extract the symptoms of the patients. Having documented the symptoms of patients, the ehealth system and services, should use these specifications to provide a list of potential diseases or conditions, causing the symptoms. At this point, when a potential cause is proposed or known, it becomes possible to provide population statistics, medical knowledge, procedures and guidelines and how doctors treat their patients with similar symptoms patterns, linked to the proposed or known causes. All the above information categories may be linked in as information resources for both the patient and the physician, showing that all information needs may be satisfied, based on access to large amounts of clinical data. It is also important that the documentation of the patient´s symptom is stored in a format that enables reuse, communication (interoperability), aggregation, and digital processing, as these information structures will be the enablers of future ehealth solutions performing computations on the patient provided symptom data. Such paradigm, the clustering of information regarding one person from different sources to keep it as healthier as possible is known as e personalised health, being centred on the patient and his Personal Health Record (Codagnone et al, 2009). Going deeper around self-care, one study (Yardley et al. 2010) has looked into this area showing that many people already use the internet for self care, but very few use the same tool to communicate their symptoms to their primary care physician(Santana et al. 2010). As more than half the population in UK use one consultation with the health care service every year for minor health incidence (30.000.000 consultations) (Health 2006) the potential for large scale ehealth solutions seems clear.

B. Disease episode types

Two broad categories of disease episode types are single disease events and chronic disease episodes with regularly repeated consultations. A lot of research is focused on chronic patients and how ehealth system can be used to support this large patient group. The other category, the single disease episode patients, is also a large group that has different needs and use scenarios, compared to the chronic patients. One obvious characteristic is that this group probably don´t want to buy or download apps to support their health communications needs, especially if they are affected by a disease. An interesting question is whether patients within this category would acquire usernames and passwords to an ehealth service to communicate with their physician? For longer disease episodes, involving hospitals treatment and

rehabilitation, follow up and tracking development or progress may easily be incorporated into ehealth solutions.

C. Disease prevalence

Frequency of usage is an important aspect as it has consequences for learning and maintaining the competence on how to use an ehealth service efficiently. It has an economical side for physicians as frequency multiplied with time consumption determines how efficient physicians are able to get their job done. If the time consumption for new solutions exceeds their current practice, it will very likely not reach large-scale usage. If we look at the communication pattern of physicians, they communicate most frequently with their patients, their pharmacies, other doctors in hospitals and health institutions, nurses, etc. For primary care physicians, the ehealth solutions should therefore focus on the most frequent communication partners, the patients and the most prevalent diseases within their patient population.

D. Computer literacy

The computer literacy issue affects both patients and health personnel. For the patients, the barrier of communicating with their physician, while diseased, may be too large. For health personnel, this issue may also be present if specialized systems for rare diseases or cases have high operating demands. For these reasons it is very important to keep very high the usability of these systems.

E. Computer usage during patient consultations

Toralf Hasvold, (former dean of the medical faculty at University of Tromsø, and pioneer in electronic health record system development and use in Norway) has pointed out that physicians should focus their attention on the patient, not the computer system, during a consultation. This guideline seems reasonable, as the diagnosis process may need the physicians´ full attention, memory and mental capacity. As the diagnosis process is complex, and the issue of how physicians arrive at a diagnosis has been researched and debated for a long time(Kassirer 1989; R. A Miller 1994; Randolph A Miller 2009), it seems safe to assume that physicians need to focus their attention on the patient and their symptoms. Following Hasvolds guideline, when the diagnosis is unknown, imply that ehealth systems should be consulted by the physicians instead of, before or after the physical consultation. This constrains how ehealth systems can be used by a patient to collaborate with his physician about undiagnosed conditions. Consultations related to a known diagnosis, as chronic diseases, follow up consultations or for monitoring, which is the major use scenario in current ehealth systems, have totally different needs, compared to the undiagnosed patient use case.

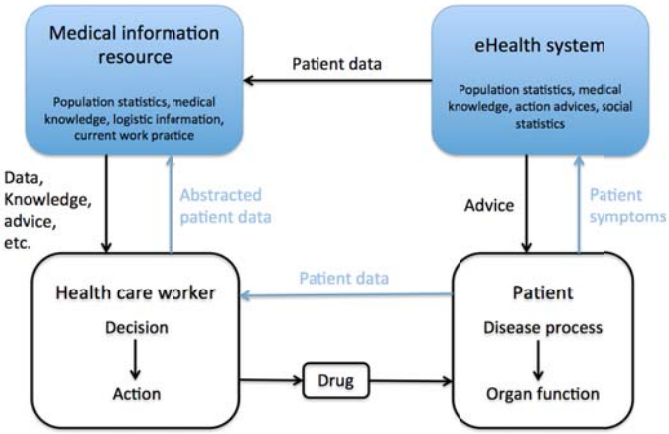

Figure 1. Human and system interaction related to medical consultations. (Adapted from Figure 1.4 in (Friedman and Wyatt 2006))

As the patient data, the symptoms, is the link to provide relevant information resources for both patients and physicians, it needs to be communicated to the physician before a potential physical consultation. Most studies investigating this area, have collected the patients symptoms while the patient were in the waiting room or at home. This will allow physicians to evaluate the symptoms and the potential treatment options before the physical consultation. By patients doing so, the documentation burden on the physicians will be reduced. If the patient is able to record their symptoms at home, symptoms may be documented when they appear, helping the patient to be accurate and remember. If the symptom documentation becomes sufficiently detailed, maybe documented several times over a time period, computing resources may be used to analyze common patterns across patient populations. Symptoms may also be documented after physical consultations, as follow up of the physical consultation. This option may be used when the doctor has insufficient documentation of the patient's condition to take a decision and therefore needs more data about the patients´ condition. This option may also be used if the physician want to see how the condition and symptoms develops to get a clearer picture; the "wait and see" option. Maybe the physician suspects that the symptoms and the condition will disappear without interventions being necessary, and therefore apply the "wait and see" alternative. It may also be possible to link the symptom pattern documented by the patients to statistics of how many patients that consulted health personnel, what diagnosis they got, what tests were taken, and what kind of drugs that were given or treatment provided, forming advices on how to act as patient and physician.

V. Discussion and Recommendations for the Future

Ehealth solutions are constrained by issues like disease prevalence, computer literacy, disease episode types, and guidelines for computer usage during patient consultations. To achieve large-scale adoption, the solutions need to focus on large scale consultation categories. The largest category with a potential are consultations that potentially could have been handled by self care, amounting to more that 30 million

consultations annually in UK (Health 2006). Most importantly, ehealth systems must provide information that the physicians needs in an efficient manner, enabling the physicians to treat more patients, in less time. As our summary of ehealth system constraints explained, all the categories of information that physicians may need, except the patient data, can be generated from processing of large volumes of clinical data. This observation should be used to guide the development of future ehealth systems in a direction that enables exploiting large volumes of EHR data. The key to provide relevant information for physicians is that documentation of the patient symptom is used as a context for providing additional information. It is also important that future ehealth systems document symptoms in a structured format, enabling interoperable communication, computerized processing, reuse, aggregation, and finally, knowledge generation from large volumes of patient symptom - physician action pairs. A very good candidate for representation of these information structures are archetypes, developed by the OpenEHR foundation (Beale 2002). Using archetypes will ensure interoperability, aggregation, computerized processing and the other requirements stated above. It will also ensure that the ehealth platform for documenting patient symptom will accept any symptom archetype specification that future ehealth systems will need, ensuring reuse of system components in a resource efficient manner.

If future telemedicine and ehealth services are specified and developed based on the provided constraints, will they succeed to become large-scale services? This naturally also depends on whether they also meet the requirement from legislation and strategies for the development of the health services. Is it likely that systems based on large volumes of EHR data stand a better chance than previous attempts to establish large-scale telemedicine and ehealth services? We think so, because such services may provide something that both patients and doctors need, links to updated and relevant information and knowledge, provided in the context that the patient symptoms provide. The physicians may have access to population statistics, relevant and current medical knowledge, the recommended guidelines and procedures, influence and be influenced by their peers and colleagues. Also, if follow up symptoms from patients can be collected and reused, evidence for the efficacy of provided treatment may also be provided, approaching the concept of a learning health system (Charles P Friedman, Wong, and Blumenthal 2010). Such information resources will also provide data from the social dimension, what have other patients´ and physicians done in a similar context. In addition, being able to establish a data resource that enables generation of knowledge from large collection of data, may also be a self-reinforcing mechanism.

Our recommendation for development of future ehealth system, based on the constraints presented above, is therefore to; 1) identify what telemedicine and ehealth systems primary care physicians need, 2) focus on the patient – primary care physician collaboration, identifying the most prevalent consultation categories suitable for ehealth, 3) establish access to processing of large amounts of EHR data, 4) enable standardized representation and large scale collection of symptom data from patients, 5) integrate the ehealth systems with the EHR systems used by the primary care physicians to establish the symptom – action pair link.

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eHealth:
New developments and services

ePACIBARD: Collective Intelligence for research in ultra rare diseases. A conceptual model

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I. ABSTRACT

In the context of the net society, the role of patients is changing from a passive to an active one: a patient with good informational skills, interest and positive attitude to cope with his disease and to find solutions for him and his family. These patients are called ePatients, and people suffering a rare disease (RD) are the best expression of them. Actually, they are the most active group of patients in Internet, sharing information about their disease or about new treatments for it, sharing experiences, and so on.

In order to understand that reality, we have to take into account the psychosocial burden associated with a RD. The suffering of these patients and their families is aggravated by psychological despair, lack of therapeutic hope, absence of practical support for everyday life and isolation, which is a main trait of such diseases. Adding all these circumstances, we can conclude that the psychological effects of a RD in the patients, and also in the whole family, are devastating.

In this situation, biomedical and social research are the most important sources of hope, but, at the same time, the research in a RD has also some determinants that have to be considered. Some of these determinants are:

- the human factor and the need to incorporate and train researchers,
- the financial factor, facilitating the sustainability in the long term,
- the access to registries,
- and the social factor, including the empowerment of patients and their role as participants in clinical studies or clinical trials.

Between the guiding principles of research in RD that could be critical, the European Rare Disease Organization (EURORDIS) highlights the empowerment of patients in research. That means recognising that patients are full and equal partners, developers and funders of research in RD.

While the mutual confidence relationship built between patients and researchers can promote the emergence of a virtuous circle in some diseases (with "high" prevalence among RD), it's possible that in the case of diseases with a "very low" prevalence we have a "vicious circle". If patients don't have hope in research, they will not be motivated to fund, support or participate in it. In the same way, if researchers don't find support, it will very difficult to break the “vicious circle” and a collective perception of learned helpness.

Web 1.0 was based in Web sites which offered knowledge and information, but where the interaction was very poor. The rise of Web 2.0 has enabled the emergence of surprising new forms of collective intelligence that could be used for research in ultra rare disease (URD). Our main objective is to promote the biomedical research in URD through the collaboration between patient organizations and researchers.

We will design a conceptual framework, the e-PACIBARD, and we will develop and apply it in a virtual platform that could be useful for harnessing the hidden knowledge from those patients (Collective Intelligence), who, at the moment, don't have the same critical mass to break the gap between researchers and patients in the same way than in the most prevalent RD.

Although we will work in one disease (the Lowe Syndrome), novelty of our project is the design of a conceptual framework and a modular environment that will allow us to apply the same methodology to different diseases.

We will define four dimensions extracted both from patient need analysis and researchers need analysis. Those four dimensions are:

- Research in Basic and Clinical Knowledge of disease
- Research in Clinical Treatment
- Research in Psychological and Social aspects
- Sustainability Module

Each of those dimensions will be represented in the virtual platform, allowing researchers and clinicians to interact in different ways and through different tools and strategies. That will be possible by analysing the needs of both (patients and researchers or clinicians) in different aspects of the diseases, and trying to find common solutions in a collaboratively way, following the work of Malone MIT Collective Intelligence Lab and their recommendations for each dimension.

At this moment, we are working with ten Spanish families. In this pilot project, PSiNET Research Group (Universitat Oberta de Catalunya) is collaborating with the Hospital St. Joan de Déu, and CIBERER (Network of Biomedical Research Center in Rare Diseases). We are working collaboratively in a team of 40 researchers (20 professionals - 20 parents) in all dimensions of the e-PACIBARD model.

Parents have been asked to fill out a set of surveys about different aspects of the daily life and clinical history (Ophthalmology, Neurology, Nephrology, Psychology, Endocrinology) in a very rigorous timetable. On the other hand, the professional researchers (from St. Joan de Déu Hospital and Universitat Oberta de Catalunya) are designing educational materials about the disease to help the parents to develop a better understanding of the disease.

In addition, professional researchers are analyzing the information submitted by parents and creating different work groups with specialists of other Hospitals, sharing with them

information and creating an open network of knowledge about the disease, following the Networked Science principles.

We will follow, then, an established scheme: there will be a retrospective part based on the incorporation of clinical data from the patient history (for example, former treatments, adverse effects to drugs, and so on) and a prospective part, although both are inseparable, as there are substantial overlaps. In any event, the participation of caregivers in the e-PACIBARD project will never interfere with the doctor-patient relationship; moreover, physicians and other health professionals have been invited to collaborate in the project by the e-PACIBARD researchers.

This conceptual model will have different positive outcomes, both for researchers and for patients /caregivers:

- User generated content: databases generated by patients of RD.
- Closer relationships among patients, researchers, and clinicians: exchange of information, increased reciprocal confidence.
- New sources of knowledge based in the “wisdom of the crowd”, or collective intelligence.
- Positive psychological outcomes between the caregivers: active role vs. passive, empowerment, hope, perceived social support, decreasing uncertainty, etc.

Our conceptual model becomes a new research path based in collaboration between patients, or patients associations, and researchers. This collaboration will be a powerful source not only for research itself, but also a good strategy for the empowerment of patients and their families.

Saluteca, a Spanish Health Video Portal

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***Abstract*—** Videos are the most common, direct and easy way to transmit an idea or a message and they are one of the more popular ways people use to create and upload contents on the Internet. Youtube is a resource that makes this possible, but one of its weak points is that it hosts many mixed videos which are of low interest and can be considered as "spam".

On the other hand, the use of Social Media is increasing in the health sector, as patients and health professionals need to answer questions and express their experiences and feelings. The lack of health information encouraged these actors to turn to social media for support and advocacy, and videos have the advantages of being engaging and easy to understand.

Saluteca is a web platform that collects trustworthy Spanish health videos from Youtube and offers them in a meaningful way. This paper describes Saluteca and explains the crawling method used to retrieve these videos from trusted Spanish channels.

I. Introduction

According to Kietzmann et.al, Social Media are "interactive platforms via which individuals and communities create and share user-generated content" [1]. Nowadays, Internet boosts Social Media with a continued growth [2, 3, 4]. People want to share their feelings, experiences and knowledge in all kind of formats: blogs, podcasts, videos... [3, 4].

Thus videos are one of the possibilities of Social Media. They are easy to record [5] and publish [6] on any device such as a smartphone which use is more extended every day.

Over 76% percent of surveyed U.S. hospitals and health systems said they use the social networking website Facebook, according to a report by consultancy firm CSC. The report also states that 65% use Youtube [7].

Youtube is a video-share website [8] that gives us the opportunity to upload and view them. Since 2005, Youtube is considered the largest and most popular video community which includes user-generated contents [9].

Users can watch and share their videos in this service web. We use this cloud service and get these resources which are loosing in an transparent abstract layer [10].

Youtube contains: videos, which are the main content of this web; channels, which are useful for organizations and companies allowing gathering a group of videos; playlists, to gather videos in a list with similar characteristics; and users, who can include their own videos, and they can also personalize and configure all their video metadatas. Tags, categories, description, geolocation, etc, are some examples of metadata.

Near 800 million unique users access Youtube, 72 hours of video are uploaded every minute, over 4 billion hours of video are watched each month, 100 million take a social action on this platform (likes, share, comments) [11].

Youtube includes a very useful documentation with many examples that help developers to create new code [12]. This makes quite differences in the quality of final results.

Besides, Youtube offers a comprehensive and complete API to personalize webs [12]. This API is available to retrieve all metadata and to embed video properties inside webs. Users can configure these properties to let developers to export their videos. It defines the way to access data and customize videos. Developers use Youtube API to integrate it into their website, to create mashups [13, 14] and even to integrate it in mobile systems [15].

The main objective of this study is to select interesting videos according to HealthTrust research [16], collecting all videos from Spanish Youtube Channels and Playlists in a Drupal platform and provide a web-based system to show these metadata and videos.

Drupal is a robust and powerful content management system (CMS) increasingly used in health communities [17, 18] that overwhelms functions and procedures including a personalized image and video. It is an open source application with huge communities contributing to their improvements.

Given the huge amount of videos available in Youtube, users may feel overwhelmed with too many contents that are usually full of “spam” (advertising, misleading videos, etc.) and other kind of useless videos. In addition users can spend too much time trying to get good videos relevant for their diseases [19].

Saluteca gathers a set of well-known channels and retrieves their videos, thus users can select a great number of videos from these trusted channels. Saluteca provides a very simple solution to a simple problem: Users need to find trusted videos from Internet. This module is a complement to the Video module that allows you to store videos locally on your site and to refer to remote videos from Youtube and Vimeo.

II. Method

We need a way to store videos using Web 2.0 platforms. In this way Saluteca features include an open source and social engineering release developed by the Northern Research Institute (Norut) and users will jointly identify videos in a controlled and secure platform.

Saluteca uses Youtube API together with Drupal CMS and crawler looks into the 22 trusted channels: Fundación del corazón, Asociación Española Contra el Cáncer, Esclerosis múltiple, Mundo bebe tv, Feder, El blog de Rosa, Ministerio de Salud del gobierno de Chile, Proyecto salvavidas, Ministerio de la Salud de la Nación, Torrevieja Salud, Fundación Josep Carreras contra leucemia, Escuela de Pacientes, Noscuidamos, Consejería de Salud de la Junta de Andalucía, Paciente Experto, Fundiabetes, Hospital San Joan de Déu, Fundación de ayuda contra la drogadicción, Madrid Salud, Salud Andalucía, Nestle Tv Bebe, Sanidad Cantabria, Ministerio de Sanidad, Servicios Sociales e Igualdad.

Before we start, we need a PHP server configuration [20, 21] (Apache, PHP setup files), Youtube API client Library [22], Drupal content type definitions that wrap youtube video entity, state type definitions to store every transition in drupal and time-based schedule (cron) to relaunch execution on each iteration.

Crawler automatically scans Youtube resources to select videos and insert them into the Saluteca web. It explores every video extracting titles, descriptions, keywords, references, categories, and other metadata, it reports back to Drupal API framework nodes and adds the information to their huge database. Finally, These nodes include them into the backbone using search engines combined with clever algorithms.

Therefore, the basic crawler steps are: retrieving the last state from the last indexing, processing 200 items video nodes on each iteration (100 to update videos from our channel with Youtube and 100 to insert new Youtube videos) and finally saving the new states to the system keeping all ready for next iteration (see Figure 1).

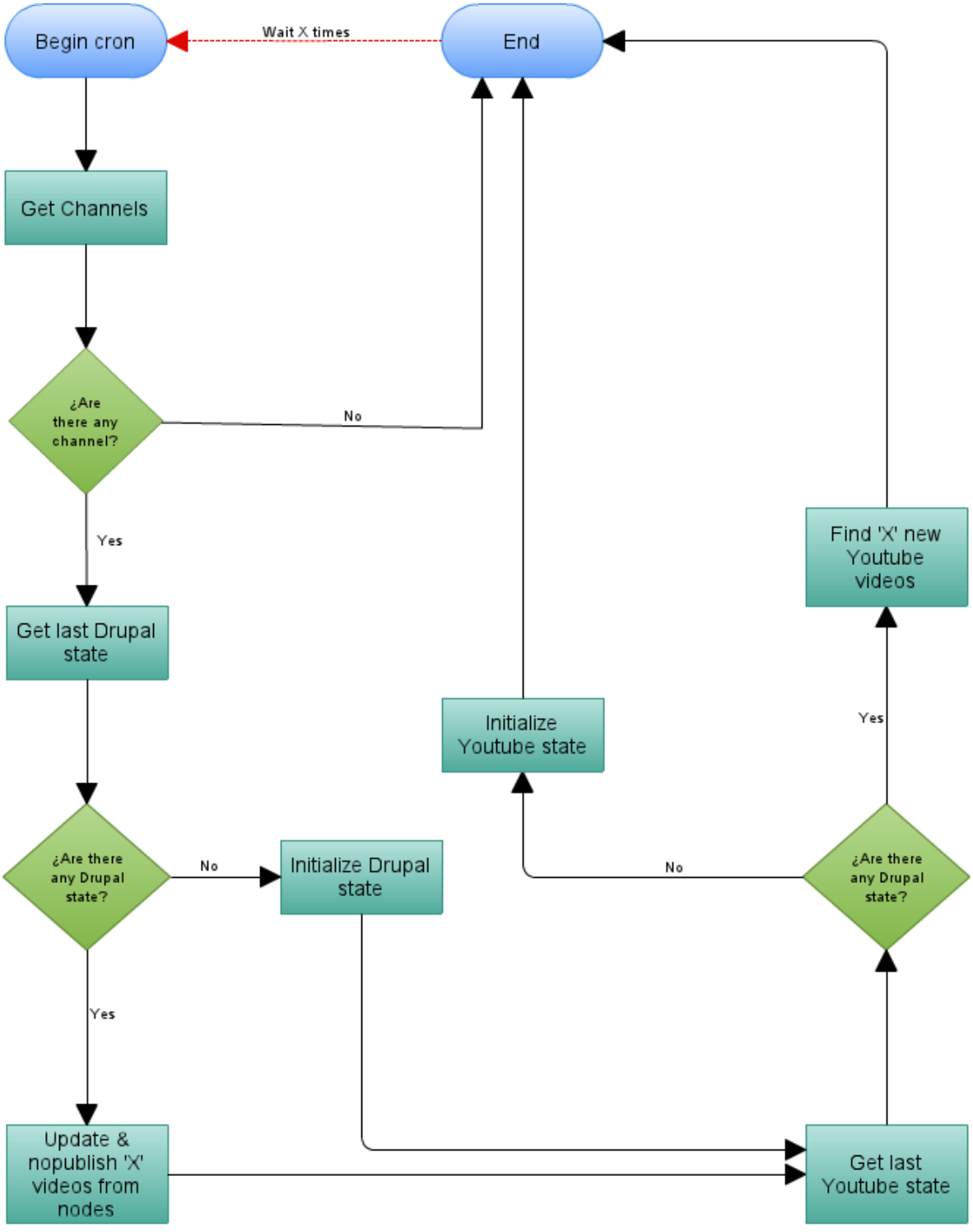

Figure 1: Main Crawler flowchart

Drupal and Youtube setups let us to show and customize videos in different ways: detail pages with simply thumbnail listings, full embed video, etc. It also provides support for retrieving and displaying thumbnail images for each video.

The system maintains a mapping between the contents, the metadata associated with the individual pieces of content, and the URL of the source from which the content was crawled.

III. Results

The results include metadata and video properties (tags, categories, description) together with the embedded video.

Our collected samples are just a fraction of the data provided by YouTube database. Saluteca offers one solution to share experiences and knowledge in a learning process between users.

We get over 1437 videos from 22 spanish channels and the crawler updates and inserts 200 videos on each iteration (1 hour). Besides, the system automatically deletes the videos selected by the authors. Figure 2 and 3 show some video example previews.

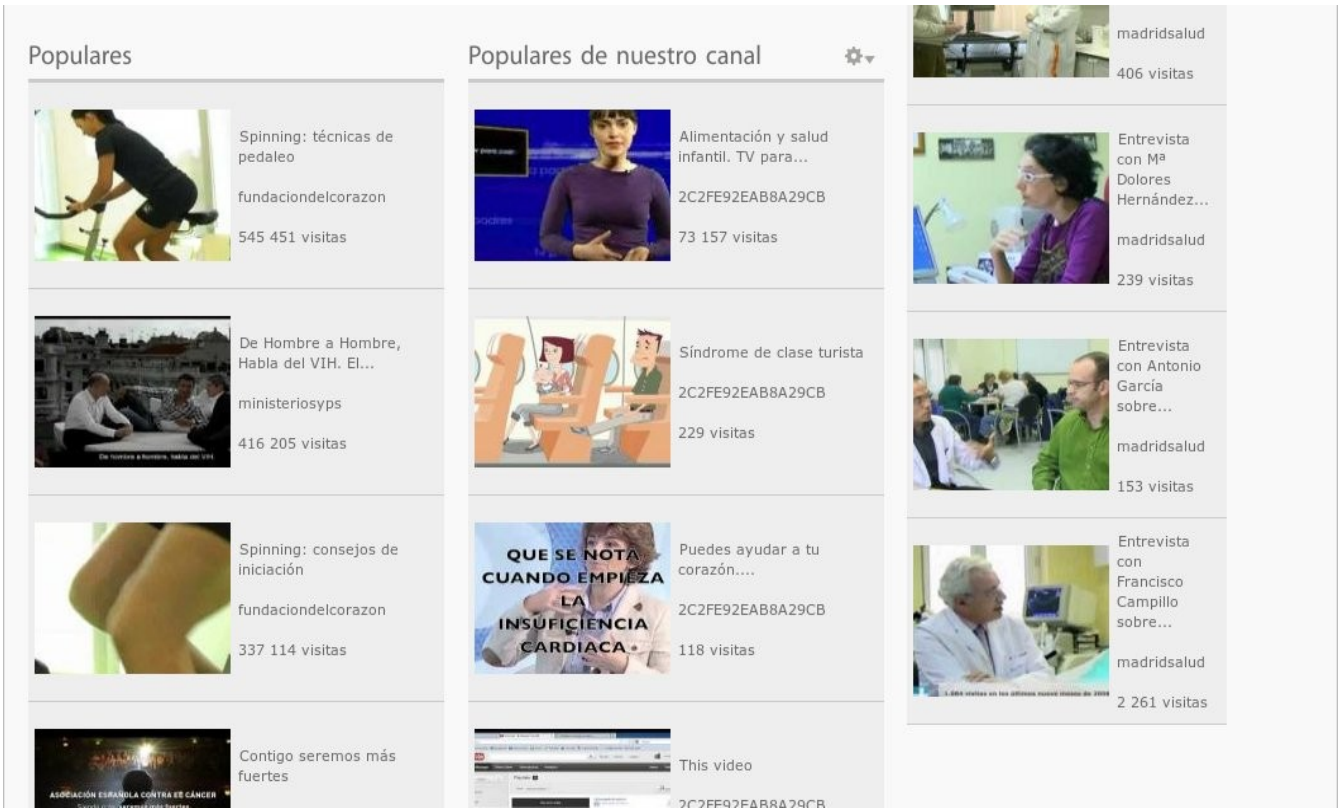

Figure 2: Saluteca preview image

Figure 3: Saluteca preview image

IV. Discussion

Youtube provides an easy way to produce mashups and use the potential and use the potential involved in audiovisual communication. We can find many Google groups who give support and quick answers too.

Youtube API [11] is well documented with good examples, however the API threshold is rather ambiguous. A limitation is the service quota: it is not properly documented and its criteria are being moidify continuously. To verify the right performance of the API service, we tested the iteration time in different ranges, as well as different amounts of videos to process.

Drupal is a stable and well documented content management system. It has forums with thousands of helpful topics [23] and over 10,000 developers show are contributing with the source code [24]. Drupal has multiple options to configure it manages the video platform. It supports embedded videos from any provider (such as Youtube or Vimeo).

Experiments on a real life dataset from our videos would demonstrate that recommender system overwhelms a better video suggestions [25], it will also be able to recommend related videos.

Acknowledgment

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Towards Integrated Personal Health and Care Services deployment in Europe

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***Abstract*— The deployment and adoption of Integrated Personal Health and Care Services in Europe has been slow and fragmented. There have been many initiatives and projects of this kind in different European regions, many of which have not gone beyond the pilot stage. We investigated 20 European Regions in search of evidence of successful adoption of such services into the mainstreaming in care pathways.**

I. Introduction

Integrated Personal Health and Social Care Services (IPHS) address health and social care needs of individuals outside of care institutions, and support the work of care providers in an integrated way. They stand on the convergence of Personal Health Systems, Telehealth, Telecare and the integration of healthcare and social care services. They integrate remote monitoring of chronic diseases, prevention and social assistance mainly for the elderly population [1]. IPHS can alleviate the socioeconomic challenges that Health and Social Care in Europe face such as demographic change, increased prevalence of chronic diseases, mobility of patients, decreasing number of professionals and rising healthcare costs. However, the deployment and adoption of IPHS has been slow and fragmented in the past years.

The Institute for Prospective Technological Studies (an institute of the European Commission' Joint Research Centre) has investigated the deployment of IPHS and their integration in care pathways at European level. The aim is to understand the necessary conditions for a successful adoption of such services.

II. Methodology

To analyse its deployment in different settings, we conducted a qualitative analysis of IPHS projects (i.e. cases) across 20 regions in eight European countries (Denmark, Estonia, France, Germany, Italy, the Netherlands, Spain, and the United Kingdom) to gather evidence in different environmental conditions and policy contexts.

The Institute, in cooperation with local agents, selected three to four IPHS projects for each selected country, resulting in the 27 cases covered this research. All cases involved almost 20,000 patients and citizens. The criterion for selection was the evidence of cooperation amongst tiers of care, or between healthcare and social care services.

A total of 96 interviews and 20 questionnaires with relevant stakeholders completed the fieldwork. The interviewees were actors involved in the initiatives, policy makers and government officers, Health Technology Assessment (HTA) agencies, healthcare managers, health and social care professionals, and some patients [2].

III. Results

Out of the 27 cases, only 11 succeeded beyond the pilot stage. We focussed on the 11 success cases to understand the conditions for successful deployment and adoption in the European regions of our study.

Concretely, success cases occurred in regions of Denmark, England, Scotland, Spain, Italy and France.

The success cases in Denmark are The Patient Briefcase in Southern Denmark and Telekat in Northern Denmark. In France, the success cases are ESOPPE in Limousin and Domocare in Champagne-Ardenne. In Italy, success cases are eCare in Emilia Romagna, Mydoctor@home in Piedmont, and Telemaco in Lombardy. In Spain, the Telemonitoring Programme of chronic patients in geriatric centres in Basque Country and NEXES in Catalonia. In England, the success case is the Whole System Demonstrator (WSD); and in Scotland, the success case was Telescot.

Denmark has been a pioneer in the use of electronic communications within each of and across the various tiers of care. The Patient Briefcase project which offers Telehealth for better breathing, deserves to be highlighted. At the time of writing this country study (end 2011) the solution had been tested with approximately 800 patients [3].

In Italy, we would like to stress the case of Telemaco, in Lombardy, with 1,000 chronic patients in a telemonitoring and teleconsultation systems. In Emilia Romagna, we found the eCare/CUP 2000, which targets 3,000 chronic patients. eCare/CUP 2000 represents a true integration of different domains such as healthcare and social services with truly

multidisciplinary user-reports created and used by physicians, nurses and social workers [4].

In the United Kingdom, Telecare is well established in both England and Scotland whilst Telehealth is not yet widespread. Significant funding has been made available to pilot and develop Telehealth and Telecare applications and the evolution of this funding allocation is also worth noting. The significant level of funding and the fact that such funding was not limited to initiating activities but significant funding was made available for further deployment has been crucial to allow for mainstreaming (e.g. the new funding made available under the DALLAS programme focuses on assisted living technologies and services). The Whole System Demonstrator (WSD) in England is the largest Telehealth pilot to date with more than 5,700 patients (including dependent people, diabetes, heart failure (HF) and chronic obstructive pulmonary disease (COPD) patients) with outstanding results [5-6].

In Spain, from a governance point of view, a royal decree was approved in 2011 imposing regional interoperability, EHR, ePrescription and cooperation between health and social care. However, IPHS implementation is still undertaken at regional level. In Hospital Donostia, Basque Country, 1,338 patients in geriatric centres and primary care participated in a randomised control trial (RCT) on telemonitoring of chronic patients care in geriatric centres to tackle dependent patients living in this type of centres. It is worth stressing the strong government push in the Basque Country where political action has been taken to promote chronic disease management including through remote monitoring [7].

IV. Discussion

The Netherlands [8] and Germany [9] show clear signs of market failure, which calls for government intervention. In Estonia [10], even if the infrastructure is in place, an emphasis on specific funding would be required for IPHS to develop. Italy, Spain and the UK which have adopted middle-out approaches (as opposed to top-down or bottom-up) often need additional governance steering [11]. In conclusion, with the exception of Denmark, and Scotland all countries still show little cooperation and/or integration of social and healthcare and need further government intervention. Generally, looking at policy and decision making, (regional) health authorities in their role as payers and healthcare decision makers need to show greater commitment through adequate regulations and, most importantly, by setting incentives.

Denmark, England and Scotland show a set of policies towards integrated care and reorganisation of services, incentive frameworks and funding mechanisms in place.

Denmark also presented higher patient side factors and higher eHealth investments than Italy, Spain and the United Kingdom. However, some projects in the latter countries also succeeded in taking IPHS beyond the pilot stage due to good cooperation between various tiers of care through governance mechanisms and reorganisation of services. Thus, different approaches may lead to success.

V. Conclusion and future research

From the cases studied, we have identified a promising trend of increasing awareness and IPHS deployment.

However, there is a need to define a common monitoring and assessment framework [12-14] for IPHS. A lot of work is still pending at the EU level in terms of defining a monitoring framework to manage the performance of policy actions and to evaluate these to improve continuous care delivery.

This framework should combine tangible (cost) and intangible (care) factors that will enable decision makers to assess both the state of maturity and the readiness for scaling. This would represent a basis for knowledge and evidence sharing as well as for a more robust comparison of performance at international level.

Acknowledgment

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Alfabetización en salud e Internet

Salupedia: a collaborative way to certify quality health information

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Salupedia is a true family medical encyclopaedia that retrieves, sorts and ranks the best health information on the Internet, created by a community of professionals and people with different roles and activities enrich and certify that information.

I. Introduction

Almost half of pysicians [1] think that online research helps patients very little or not at all, and just 8% think that it is very helpful for them. 29,9% of Spanish individuals use Internet for seeking health related information [2]. This percentage raises up to 48,3% [3] when Internet users were asked about.

There is a huge amount of people searching health information but they can´t recognize useful and valid information on their own.

II. Approach

A. Patients

People search on Internet for health information. We need to put reliable information that can be easy to found, validated by healthcare professionals (doctors, nurses, pharmacist), written and oriented to ordinary people.

The system must recommend similar or related information. Patients should have the possibility of share rate and comment this information.

Patients have the motivation they want specific information about their pain (or someone near). Although they trust at first in their doctors, also they want to know more and consult the Internet [4].

So, Salupedia (Fig 1) provides Health-related information on chronic illnesses and other conditions, responds to Health seeking behavior and empowers participation. Salupedia creates a user community where health professionals (doctors, nurses, psychologists...) and citizens more easily incorporate preventive activities, better still get your medication and greater clinical benefit when they understand what they experience and engage in their healing process. To recommend contents, existing but dispersed in the network, for patients, families and citizens in general, is a unique and enriching experience for both groups.

Fig 1 Salupedia web site

B. Healthcare Profesionals.

One of most important tasks of healthcare professionals is to provide information and educate in healthcare.

Best results are obtained from citizens who understand and get involved in their healing process. So, health literacy is a better predictor of health status than age, income, employment, ethnicity, or educational level [7]. Low functional health literacy is associated with a wide range of adverse health outcomes [8].

In this way, people find a place to access reliable information on health, recommended by professionals. The professional, in turn, have a trusted place where leading their patients when prescribing want information.

C. Technology

We created an MVP pattern in PHP with MySQL for a fully dynamic and database-driven website.

Links to the recommended documents have been categorized by subject and by predefined keywords (markup-tags).

Various tools have been developed for health professionals and for e-patients and the ability to create alerts to be notified by email when there is new content of interest or professional writing reports for searches performed on the system that does not get results.

III. Results

The Web platform ww.Salupedia.org has been created as a collaborative tool, using web technologies that allow healthcare professionals recommend (prescribe) and share information they consider useful. And it also constitutes a trusted place where direct patients involved (empowered) to find information recommended by other professionals.

We reach more than 4 millions pages viewed, 380 thousand unique users [6]. Over a 1400 registered users (three hundred are healthcare professionals) and it has more than 600 articles available.

Over 10% conversion rate (user that continues to the full information article)

Daily average is around 3,500 pages viewed. The registered user participation is still low, and only 3% of registered professional users generate 91% of the site's content. 9% of visitors follow the link that contains the original information linked from Salupedia

Even physicians know how important is the prescription of information, most of them (89,5%) just register on the site but don´t recommend any information.

Internet information research Patient have motivation is complementary of medical advices.

After two years, we are still working to improve quality of the tool.

IV. Conclusions:

Patients and professionals need reliable information to prescribe Internet.

Internet quality information has always been controversial, and different tools have been implemented to try to validate it (Fig. 2).

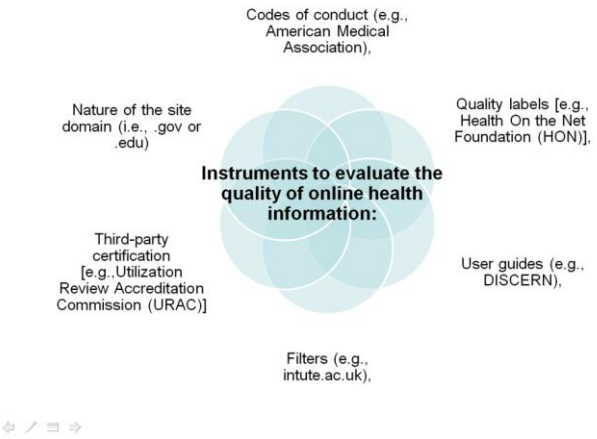

Fig. 2 Instruments to evaluate quality of online health information [5].

Salupedia can be a useful tool for assessing the quality of health information on the Internet, through the collaborative work of health professionals and patients. Currently, efforts are focused on improving participation rates of users. The participation rate is low but the following of the links shows that the tool does bring healthy information to those who need it.

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TIC, salud y sanidad

What doctors and patients need from new communication tools

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Health is a topic which concerns us all as human beings, and when our health or that of our loved ones deteriorates or is at risk of deteriorating, we search for information in the media which is readily available to us.

A few decades ago, social communication media such as radio and television played this role, but today the Internet has taken over for these traditional media, becoming the main tool we use to look for information on health.

This tool is used by both doctors and patients, but we access different types of resources when seeking information.

When discussing what patients require, we must not fail to mention the first e-patient ever, Dave deBronkart [1], who brought up a series of requests for both us health care professionals and the available communication tools:

1) Patients must be considered the main diagnostic tool, and an active role must be assigned to them in the health care process ("Let patients help"). [2]
2) Quality health care information sources on the Internet intended for patients.
3) Access to health care data.

For decades now, having patients play an active role in their healing process is something which we have been taught and teach to new classes of health care professionals, but it usually comes in the form of a "declaration of intentions" and not something we actually carry out in our offices, as a general rule. We continue to display the attitude of protectors and managers, leaving little room for patients' active participation and self-care. The Internet has revolutionized the potential for accessing information, though, and as a result patients have turned themselves into "e-patients" to a greater or lesser degree [3].

Thanks to the Internet, patients have organized into virtual communities in which high-quality information on health care is exchanged. They are usually run by expert patients who create a positive dynamic for the community. These communities must also be a tool that we are aware of as health care professionals, because they play an important role in training and enabling patients throughout the process of their illness or disease. In order for a virtual community of patients to be successful, it must possess a certain set of features [4]:

1) It must be run by an expert patient who is highly motivated.
2) It must provide access to high-quality health care information written in a way that can be understood by non-health care professionals.
3) It must create motivation for active participation by all community members.

In the United States, there are many examples of highly active patient communities, which provide very high-quality information. In Spain, however, they have not been as successful as was expected.

So, how can patients get quality health care information? Perhaps we as health care professionals should accept a part of the responsibility in this task. The best way to fight off the effects of low-quality health care information may be to create information of an excellent quality and get it properly positioned in Internet search engines. In this sense, all of us health care professionals must play an active role, whether by producing contents or disseminating other people's contents through social networks, to help them get better positioned online. By doing this, a time will come when the "good information" will appear higher than "mediocre information" in searches, allowing independent, truthful health information to be more visible than health information which is provided with other, hidden purposes more related with sales and the market than with people's health.

However, in addition to seeking information on their disease or illness, patients want to communicate with health care professionals in a fast and efficient way, and in the least amount of time possible. Meanwhile, we health care professionals also want flexible systems for communication with patients that require few resources. All in all, both doctors and patients want to communicate with each other using tools, which are:

1) Technically efficient (fast, user-friendly, low-cost).
2) Secure in terms of confidential or private date transmission.

The revolution that has taken place in communication has affected all of our everyday lives. We all currently communicate through tools based on Internet technology, including voice on IP, video-conferencing systems, instant messaging and social networks. Among patients and health care professionals, we must create communication mechanisms which, being fully compliant with the legal and ethnical principles governing health care information, meets our needs, thereby becoming ideal channels of communication.

However, we professionals are also seeking information and resources using Internet-based tools, as well. At present, we have two important needs, which are getting fulfilled more and more often:

1) Contact with other professionals through social networks, whether they are specific networks for health care

professionals or groups of health care professionals in general social networks.

2) Looking for information that answers specific questions, which arise in practice, or more extensive information for study and consultation.

Social networks for health care professionals are gradually taking on their proper role in our country, though it is also true that we organize better through spontaneous groups in general social networks.

Applications for mobile devices, known as “apps,” are undergoing a great deal of development in the health care field. It is estimated that their growth will be exponential in the upcoming years. In Great Britain, the National Health Service has carried out campaigns that specifically support these applications, and in early 2012 it set up a system for participation by all of the professionals in the health care system to select the best applications [5]. In the United States, the Food and Drug Administration (FDA) has published a guide on medical applications [6].

The applications for mobile devices can be classified academically into four broad groups [7]:

A. Applications for use in the doctor’s practice: flexible, simple applications that provide an answer to specific questions by health care professionals (medical calculators, medicine interactions, diagnosis aid systems, etc.).
B. Applications for study and consultation, such as books, scientific journals, atlases, clinical practice handbooks, etc..
C. Applications dedicated to patients: applications which build on the knowledge and skills necessary for patients to get help when they decide to take on an active, participatory attitude in their healing process, or to begin living a healthy lifestyle.
D. Applications associated with other health care devices such as glucose meters, blood pressure meters, stethoscopes, scales, electrocardiographs, etc., or any type of device whose output signal may be produced digitally.

As both a professional and a patient, I ask those who develop applications, and the public and private entities responsible for their quality, to ensure that:

1) The information provided is true and independent, as well as being properly adapted to health of the final target population.
2) They are flexible, easy-to-use tools that can be consulted quickly.
3) The information is adapted to the knowledge and needs of the application’s end users.
4) Regulatory mechanisms are created so that the quality of content is appropriate

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Accessibility in Health related Virtual Learning Environments

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I. Introduction

Supporting patients and informal carers is an essential task in managing chronic diseases. Many of these diseases are either directly linked to disabilities or are age related and, thus, also strongly correlated with potential disabilities. Furthermore, as the population ages it is becoming more and more common to give an old person with a set of mild disabilities acting as informal carer of another person with some type of chronic disease.

Support material and professional help can be provided through the use of an eLearning platform. These platforms are usually known as Learning Management Systems (LMS) or Virtual Learning Environments (VLE). People with disabilities, linked to physical and/or cognitive impairments can obtain an extraordinary advantage from access to eLearning but, in practice, they find important barriers when the Virtual Learning Environments (VLE) and contents are not delivered in the suitable adapted forms according to their needs and preferences.

All VLEs are supported by a set of different technological layers. Those layers can interfere with the final user gaining access to such adapted resources. Conflicts with user agents, assistive technologies and the delivery format of the resources are the most common problems.

The accessibility of current VLEs, a mature technology, provides an interesting case study regarding the types of problems that can be encountered by users in current web applications", (Power et al, 2010).

II. Accessibility Evaluation

In order to evaluate if a service or environment is accessible to as many people as possible it is necessary to undertake accessibility and usability verification.

A basic evaluation could be based on automated checking of conformance to guidelines and standards. In some cases these are implemented as legislation, e.g US rehabilitation act Section 508, and in others as standards like ISO9241 or W3C Web Accessibility Initiative guidelines.

The use of guidelines to accomplish accessibility evaluations is widely discussed in literature. Many authors (Kelly et al., 2005)(Sloan et al., 2006)- agree that the development and promotion of guidelines for Web accessibility has been fundamental to the increase in prominence of Web accessibility and find guidelines particularly effective as a basis for automated assessment of those accessibility barriers that do not require human inspection. Other authors (Nielsen, 2005)- criticize the guideline-based approach for having significant shortcomings.

As a matter of fact, researchers have found Web sites that rated highly on user performance and acceptance measures, yet which did not conform to some high-priority WCAG checkpoints. Equally, there is also evidence that accessibility guidelines can be applied literally without consideration of the impact of the solution on usability for disabled people (Thatcher, 2003). This was specially the case before the development of the WCAG 2.0 as the previous version of this guideline was based on checking a set of very specific criteria that were not always adapted to the diversity of the real users and the very fast technology changes that are typical of internet based services.

Finally, one well proven method to improve universal access is by involving final users during the whole design cycle. However it is clear that this is the most expensive approach. Although it is recommended by many authors e.g. (Wattenberg 2004)-, it also has are several challenges. Apart from cost, user recruitment (Petrie et al., 2006) and representativity are also problematic. .

III. Accessibility Guidelines

There are several specifications and guidelines to be considered in order to promote accessibility in VLEs:

- W3C Web Content Accessibility Guidelines WCAG 2.0 (W3C WAI, 2008)
- W3C Authoring Tool Accessibility Guidelines ATAG (W3C ATAG, 2000)
- W3C User Agent Accessibility Guidelines UAAG (W3C UAAG, 2008)
- IMS Guidelines for Developing Accessible Learning Applications GDALA (IMS GDALA, 2002)
- IMS Learner Information Package LIP, and Access For All v2.0 (IMS LIP, 2002)
- ISO FDIS 24751 Accessibility standards (ISO FDIS 24751, 2008)
- Section 508 of the US rehabilitation act. For our purposes this is very similar to the W3C WCAG requirements.

In such a complex scenario, it would be useful to know which are the guidelines, specifications and standards to be used in every learning phase. The main applicable

specifications and guidelines are further explained in the next subsections of this paper.

A. W3C General Accessibility Guidelines

The W3C Web Accessibility Initiative (WAI) mission is to develop strategies, guidelines, and resources to help make the Web accessible to people with disabilities. As VLEs, which are our main element to support patient and carer training, include most of the major tasks on the web, WAI guidelines suit the usability and accessibility analysis needed by eLearning containers and contents.

One of the guidelines that is more useful for our objectives is the Web Content Accessibility Guideline (WCAG). This guideline groups recommendations into the goals of developing perceivable, operable, understandable and robust web contents. Nevertheless, in the case of training systems there seems to be an implicit request to enlarge the scope of the accessible concept because guidance to teachers was found to be mainly targeted towards technical (Bel et al., 2008: 1028).

B. IMS Specifications and ISO Standard

As mentioned above, in 2010 IMS published two documents based on ISO/IEC specifications (IMS GDALA, 2002) and (IMS LIP, 2002) which were based on previous releases of IMS Access For All.

The first of these documents, Resource Description Information Model (IMS A4A, RDIM, 2010) focuses on the definition of a platform independent model (PIM) that provides a common language to describe digital learning resources to facilitate matching these resources to the learners' accessibility needs.

Access For All specifications assume that the eLearning content is compliant with basic accessibility specifications although in 2002 IMS GLC also published their own Guidelines for Developing Accessible Learning Applications that highlight existing solutions in order to provide a framework for the distributed learning community.

Some state of the art work has been undertaken to implement compliant tools, such as “ATutor”.

IV. Accessibility for VLEs

In order to study the Accessibility and Usability of real world VLEs, there are some key issues which should be thoroughly considered, (Martin et al., 2007):

1. VLEs are complex systems, which have to meet some specific requirements:

(a) to be flexible enough to address a variety of teaching styles, interaction preferences and devices; (b) to offer a wide range of configuration options; (c) to comply with educational standards –e.g. IMS, SCORM-,.

2. Accessibility and usability evaluations must be planned ahead for the entire eLearning Lyfe Cycle.
3. When evaluating the overall accessibility and usability of VLE, three different elements must be taken into account: the platform, where the course materials are stored and delivered; the packaged course materials, and the content generated by users.

It is important to understand that there are mainly two methodologies for obtaining accessibility data about VLEs: survey and interview approaches (Hersh, 2008), and empirical analysis (Power et al., 2010).

V. VLEs accessibility analysis results

There are not many studies VLE accessibility despite its importance for universal access.

In a general study (Dunn, 2003) higher education stakeholders were asked to answer an online questionnaire and its results were used to plan a series of in depth interviews. It is interesting to remark that fifteen percent of respondents considered accessibility as a criterion to be 'considered but not primary' for their choice of VLE.

A more recent study about VLE accessibility (Power et al., 2010) analyzed three commonly used VLEs: Moodle (version 1.9), .LRN (version 2) and Blackboard (version 8). A double approach was undertaken.

First, a heuristic evaluation of these tools based on [WCAG 1.0] guidelines was carried out. All systems included violations in all the priority levels. Blackboard got the worst accessibility results but the differences were not very significant

A second step was an end user evaluation using the same VLEs. Four blind, screen reader users, were asked to undertake a set of defined and representative tasks in the VLEs. The results of this experimental study match with the guidelines evaluation in most cases. For instance, participants struggled with Blackboard more than with .LRN or Moodle. However, in general Moodle and .LRN are better rated in this second evaluation than in the first one.

The main outcomes concerning general VLE accessibility and usability issues from (Power et al., 2010) are:

- There are serious accessibility issues related to the use of virtual learning environments in current practice. Even though only a small subset of WCAG 1.0 checkpoints were tested on a small subset of tasks the tested VLEs did not pass even the lowest compliance level
- Each tested VLE had accessibility problems that did not allow some users to continue without external help when they were performing some of the basic tasks.
- There is a need to educate the individuals developing, deploying and procuring these environments about accessibility and which criteria to apply when adopting a VLE.

- There is a clear need to examine accessibility in VLEs looking at the industry's attitudes.

In order to complete and update the analysis of VLE accessibility a survey has been undertaken in the framework of the CARDIAC EU (CARDIAC 2010) project. As a result of the analysis above it was decided that to get VLEs that could be realistically used as training systems for chronic disease patients and informal carers industry would have to embed accessibility into VLEs and they should be able to interact with common assistive technology. These reflections lead us to the question that we wanted to answer: "What mechanisms would ensure successful integration of accessible and assistive ICT products, services and standards in VLE and eLearning?". The result led to the following conclusions:

- To have a successful accessible VLE (or any other accessible web app or service) it is essential that accessibility be built into the web design tools.
- The role legislation (push or pull) will play in the future of accessible systems can´t be underestimated.
- It is essential that the designers and end users are aware of the fact that users with some disabilities will be using the system. Even with the best automatic tools awareness of this situation is important.
- The trend of accessing internet based services through many different devices, which requires all kind of contents to be accessible through them, presents a clear opportunity, as well as a challenge, for accessibility.
- Many experts considered that it is not possible to go in a single step from the current situation to fully accessible systems. In the case of chronic disease patients and older trainers the support system should at least contemplate the situations that are more common. E.g. it is clear that to support patients with diabetes the system should be accessible by low vision and fully blind users.

VI. Conclusions

VLEs represent a very good alternative for building training support systems for chronic disease patients and their informal carers. However, due to the characteristics of the target users accessibility is an essential requirement for these systems.

Our study analyses through literary revision and expert's interview the situation of several common open source and proprietary VLEs. From this analysis we conclude that current VLEs are not fully suited for our intended target groups but solutions to ensure at least accessibility for selected target groups can be implemented using them.

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Posters

Concept maps in the Knowledge management as a basic competency in the key of health technologies.

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***Abstract*— Knowledge is one of the most important values to achieve sustainable success in any organization. The ability to acquire information, transform it into knowledge and incorporate it into the company, is a vital pillar to face market competition, preserve their position and achieve a state of continuous improvement.**

A powerful tool for this function is the concept maps for organizing and representing knowledge on the key issues of health technologies.

This tool includes concepts, relationships between concepts, linking phrases and words, objects and events.

I. INTRODUCTION

This document is a based to study a Concept Maps. There are a graphical tools for organizing knowledge, issues of health technologies.

The first tool is a concept, as a perceived regularity in events or objects, or records of events.

In knowledge you can use linking words or linking phrases, referred to words on the line. Specify when there are relationships between two concepts.

Other examples are semantic units or units of meaning.

The concepts are represented in a graphic and static fashion, moreover the inclusion of cross-links are statements about objects or events in the universe.

II. OBJETIVES

The concept maps are important in the learning process on the key of health technologies, where the attributes of concepts are identified by the learner, and the reception learning process, where attributes of concepts are described using language.

Ausubel made the very important distinction between rote learning and meaningful learning.

TABLE I: **OBJECTIVES**

1	**Being visual tool ensures better integration.**
2	**Feedback on integrated learning processes.**
3	**Reduced training costs.**
4	**Increased effectiveness and efficiency.**
5	**When using this tool in business strategy, processes are synthesized.**
6	**Search what we know based on existing sources.**
7	**Check results.**
8	**Normalize.**

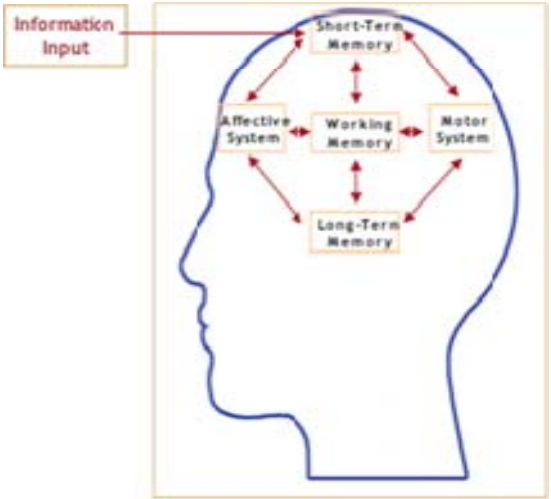
Concept maps can be helpful to learn about health technologies.

The material to be learned must be conceptually clear and presented with language and examples relatable to the learner's prior knowledge.

The learner must possess relevant prior knowledge.

III. STRUCTURE

Reasons. Why the concept maps are important in the learning process on the key of health technologies



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IV. SPECIFIC METHODOLOGY

TABLE III

COMPETENCIES ON THE KEY OF HEALTH TECHNOLOGIES

Nª	**COMPETENCIES**
1	Motivation
2	Intention
3	Arousal
4	Feelings
5	Emotions
6	Engagement
7	Attitude
8	Abilities
9	Beliefs
10	Values
11	Social pressure
12	Talent
13	Experience
14	Skills
UNDERSTANDING	
1	Behaviour (What is observed).
2	Performance
3	Performer level
4	Organizational level
RESULTS - IMPACTS	

V. CONCLUSIONS

1	**Being visual tool ensures better integration.**
2	**Feedback on integrated learning processes.**
3	**Reduced training costs.**
4	**Increased effectiveness and efficiency.**
5	**When using this tool in business strategy, processes are synthesized.**
6	**Improved internal and external communication.**
7	**Improving the quality of management.**

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