

SANITAS CHAIR OBSERVATORY ON E-HEALTH

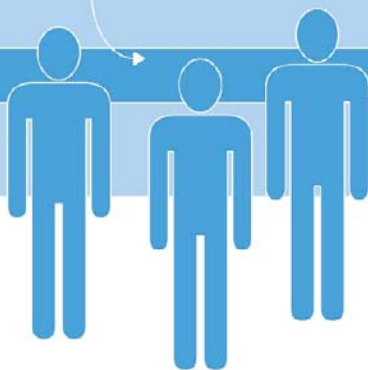


2009 REPORT

SURVEILLANCE REPORT ON HEALTH AND WELLNESS ONLINE SOCIAL NETWORKS



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EXECUTIVE SUMMARY

CÁTEDRA SANITAS
"TECNOLOGÍAS DE LA INFORMACIÓN Y
LAS COMUNICACIONES PARA LA SALUD"

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Report by:

Sanitas Chair (www.catedrasanitas.org)

**High Technical School of Telecommunications Engineering,
Technical University of Madrid**

Report Authors

- Diego Ruiz Quejido (Director)
- Isidoro Padilla González
- José María Caveró Clerencia
- Luis Ignacio Vicente del Olmo

Collaborators

- María Moríñigo González
- Gonzalo Parra Mediavilla

EXECUTIVE SUMMARY

Introduction

The growth in Internet usage around the world continues apace. In Spain, the number of users rose by 11.3% in 2008 and it is estimated that 56.7% of the population aged 16 to 74 has employed the technology, i.e., 24 million Spaniards.

The Information Society also continues to evolve, largely as a result of this online development. The Information Society (IS) is understood as a period of social development characterized by the ability of its members (the general public, businesses and the public administration) to obtain and share any information, instantaneously, from anywhere in the world and in the form they prefer.

Propping all of this up are the Information and Communication Technologies that form part of the 'second generation' of web-technology development, i.e., the 'Web 2.0 generation', which involves a huge leap forward from the first generation. The original web environment was a decisive instrument in determining the ongoing rise of online penetration but its features were limited practically to searching and consulting multimedia content, relegating users to a passive attitude. Web 2.0 has enabled the development of a user-participation-based open platform which fosters flexible collaboration and the exchange of information between users and where there is space that provides them with the ability to create content (personal or collaborative) and which allows them to share, exchange, consult, integrate and assess information. Web 2.0 as a level of evolution is being overtaken by 'Web 3.0', which will include further technological breakthroughs over its predecessor.

It is easy to understand how the factors that characterize Web 2.0, together with the incremental penetration of the Internet, have fostered a natural expansion in spaces where content is created and shared, or other series of activities are done, which in turn impacts particular information such as that found on blogs, wikis and online social networks, the

object of the present study. It is a concept that defines the virtual social structures that result from interactions between Internet users linked by common information or interests.

The e-Health approach, which can broadly be understood to include applications deriving from the use of ICTs in healthcare issues and the use of the Internet in health practices, has also been affected by the appearance of Web 2.0 technologies, fostering a new approach towards interactive health and among its agents by providing the technological tools that make it possible for users to generate and share health-related information and content and manage their own health, as well as promote better education and, in short, encourage enhanced collective knowledge in a collaborative fashion. E-health will also contribute to providing the tools that permit the different aspects of the health environment to become more flexible, cost-effective, interoperable and integrated, improving its efficacy and efficiency. When this comprehensive approach towards interactive health knowledge is complemented by aspects of work/social information among the different agents, it can be called 'Health 2.0', associated to which, of course, we see Health and Wellness Social Networks appearing.

Health and Wellness Online Social Networks

The profusion of social networks in general and those targeted at health and wellness in particular made it necessary to limit the number of sites to analyze in the present technological surveillance study. However, this is no barrier to identifying approaches with high added-value and more or fewer differentiating aspects between them. In almost all cases we can say that Health and Wellness Social Networks are spaces for the exchange of information and experiences, patient discussions and education; spaces

not lacking in a highly emotional capability where people can find support, aid or comfort from the rest of the community.

These capabilities which we consider common on the networks studied here and which are structured around the basic set of Web 2.0 applications, such as forums based on e-messaging services, chats, blogs, online newspapers, visitors' books and spaces for sharing photos or videos, and which contribute to more faithfully transferring personal conditions from a patient to other people, are complemented with other more specific tools that comprise the differential approaches most of the analyzed networks take.

These networks include other facilities used in a shared, comparative and interactive fashion by the various agents involved (usually patients, doctors, carers, other health personnel and family and friends). Some include:

- Tools that make it possible to transform patient experiences into records (with regards disease evolution, symptomatology, treatments, response to treatments, conditions) so they can be followed and turned into easily viewable graphic formats, compared against others or used in sharing notes on patient conditions with the medical professionals who attend them.
- Powerful pain-management tools, where, via graphic applications and interfaces, patients can report conditions, find automatic protocols (or find them with the assistance of physical persons) for their treatment, see their evolution, share information with other members, manage action diaries, etc.
- Carry out consultations with health professionals, in real time or otherwise.
- Networks targeted exclusively at medical professionals, providing them with a space to exchange experiences and access publications or matters related to training and positioning.

- Networks that permit the creation of other sites at a smaller and more specific level.
- Publications, newsletters, guides, videos on diseases, tools for preparing surveys and tests that make it possible to carry out research work, see the progress made with regards different diseases and responses to new drugs and protocols, even before they are released by the official authorities.
- Networks that act as search-engine browsers, facilitating the identification and sharing of the best knowledge available on the Internet.
- Tools for self-testing and self-monitoring and health tools and trackers that provide users with a range of health services and associated healthcare providers, supplying facilities for evaluating their quality and price and including simulators to adapt them to user specificities.
- These facilities observed in Health and Wellness Social Networks, analyzed from the user's viewpoint, are complemented to a greater or lesser extent by other facilities also afforded by ICTs, such as tools for designing user webpages, tags, RSS feeds, widgets, etc., and elements aimed at getting users to trust in the reliability and quality of the network in question on the basis of accreditations awarded by competent authorities, or that provide information on the facilities available or how the network's governing bodies are composed (management boards, R&D teams, technical committees, publishing companies, advisory committees) to confer an image of transparency

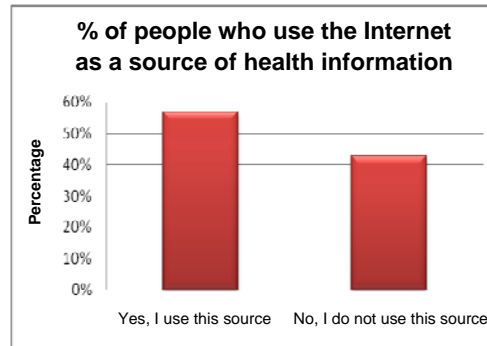
The conclusions of our analysis of Health and Wellness Social Networks confirm that the Internet, as a paradigm of information and communication technologies, is changing our view on health and healthcare in general, and facilitating new scenarios for relations between the different agents involved, i.e., patients and people in their personal environment, professionals, public

administrations and providers. These networks are one of the pillars on which new forms of the doctor/patient relationship are being forged in our society and on which new applications that make it possible to optimize processes between them are being built, along with their results, knowledge and training. That is the value of the present study – it shows the state of the art and best practices among these networks, promoting reflection and the opportunity to build and utilize them.

Although it is true that the Spanish approach towards healthcare differs greatly from the American one, the enormous development of Health and Wellness Social Networks in the US is undoubtedly a reference point and sets the standard about how our environment may be expected to evolve.

One example of the extent to which the Internet is being used for health purposes is found in a recent survey for the report entitled the “Pew Internet & American Life Project: the Social Life of Health Information”. In the year 2000, 46% of the adult American population had access to the Internet and only 25% searched for health information online. Now, with 74% of American adults using the Internet, 61% employ it to find health-related information (e-patients). This shows how popular Health 2.0 is becoming. In Spain, it was found that 41% of Internet users searched for health-related content in the year 2007.

The search for online health information is already an unstoppable phenomenon. The abovementioned report shows the extent to which this is happening: when an American adult needs to find a source of health information, he looks online. 57% of the people polled said they turned to the Internet for information or help in health or medical matters.



Source: *Pew Internet & American Life Project Survey. Methodology (19 November – 20 December 2008).*

This means that the Internet is the third most-popular source of health information, behind visiting a health professional such as a doctor (86%) and asking a friend or family member (68%).

In total, 60% of e-patients, i.e., 37% of American adults, have been involved with social media activities related with health and healthcare. Online social networks have thus become another tool that people use in these aspects of their daily lives.

This scenario shows a perspective of growth in breadth and profundity for Health and Wellness Social Networks (not to mention what it says about general social networks such as Facebook or Twitter) which warrants being taken into account by the members and designers of healthcare models. It seems not only to be necessary to consider the incorporation of IT tools for the automation and flexibilization of processes in its evolution but also the new frame of relation for the creation and exchange of knowledge between agents, a frame of relation in which the online social networks that are the object of this study will undoubtedly play a large role, helping not just patients and their families to have a better quality of life but also aiding sector professionals in training, research and exchanges of experiences.

Online searches of health-related issues

Percentage of Internet users who have looked for information on different issues

	People who live with a handicapped or chronically ill person	Non-chronic patients	All
Specific disease or medical problem	73%	62%	64%
Certain medical treatment or procedure	64%	49%	51%
Diet, nutrition, vitamins or nutritional supplements	53%	48%	49%
Exercise or fitness	46%	44%	44%
Prescription or over-the-counter drugs	51%	35%	37%
A particular doctor or hospital	33%	28%	29%
Health insurance	30%	28%	28%
Alternative medicines or treatments	42%	25%	27%
Depression, anxiety, stress or mental health issues	30%	21%	22%
Environmental health risks	24%	21%	22%
Experimental treatments or medicines	30%	17%	18%
Immunization or vaccination	13%	16%	16%
Dental health information	16%	14%	15%
Medical care	24%	11%	13%
Sexual health information	11%	11%	11%
How to stop smoking	18%	8%	9%
Problems with drugs or alcohol	8%	8%	8%

Source: Pew Internet & American Life Project Survey. August 2006

Study Sphere of Application

The present study was aimed at analyzing websites related with the exchange of online information about health and wellness for people. Bearing in mind that the issue which is the object of this technology surveillance study is very broad and dynamic, its scope was delimited considering three aspects:

TECHNOLOGIES

ICTs belonging to the IS (targeted at the public) dedicated to the exchange of information about Web 2.0 technologies.

SERVICES

Online information (how the public collaborates, interacts and shares information, as well as to what end and what

extent) that generates collective knowledge on health and quality of life.

USERS

The public (patients, people in their personal environment, carers, health professionals), access to information and consultations.

This selection was made to identify the number of social networks/sites, i.e., communities that act within the limits defined by the previously mentioned factors, which make it possible to deliver on the study goals in a particular and useful fashion: systemization of data, technologies, processes and methodologies used.

This selection was also enhanced by identifying sites with the minimum set of tools and applications that characterize social networks:

SOCIAL NETWORKING SERVICES

- Creation of user profiles.
- Own contact list.
- User-to-user communication and interaction mechanisms.
- Generation, publication and consultation of own content.

In short, therefore, the goal of the report focused fundamentally on an analysis of sites that offer social networking services related with online information about health and wellness, in line with the four aspects mentioned above. As also mentioned in the executive summary, the importance of these sites lies in their contribution to the construction of open and collaborative collective-knowledge platforms (2.0), equipped with very powerful tools, with access for all members of the public. However, there are other sites that also contribute to this same social goal even if they do not have all the characteristics of Social Networking Services, built with Web 2.0 technologies, and which also, where considered relevant, were considered in the report.

- PORTALS: Which permit access to information and have forums for interactively posing and answering questions.
- BLOGS: Which make it possible to upload and share content.
- WIKIS: Which permit collaborative content creation.

Functional Analysis of Social Networks

Having delimited the study scope on the basis of the criteria mentioned above, the particular selection of sites to analyze was done via a preliminary identification of the most important social networks, using criteria involving number of users and how well known they were in Alexa, one of the most

popular and broadly accepted assessment tools on the Net for these purposes. In this preliminary identification we detected 36 social networks that focus on aspects of health and wellness. Comparing this list with the health sites referenced on other portals and by specific organizations such as the California Health Care Foundation gave us an initial panel of 30 sites of interest for the purposes of this report. The number of networks was finally reduced to 19 after eliminating those of a general nature or which were in the process of being reviewed. Once the report was finalized, this group was found to be significant in light of the conclusions obtained.

Below is a summary of the approach and differential aspects of each.

DAILYSTRENGTH (Social Networking Site. USA)

This site (www.dailystrength.com) is fundamentally aimed at facilitating access to information on the Internet, the exchange of experiences and emotional support. It has a powerful forum-management tool (covering over 500 forums) involving site managers and members. It also has facilities to make real-time consultations with health sector professionals.

EVERYDAYHEALTH (Social Networking Site. USA)

Part of WaterfrontMedia, one of the biggest private American on-line health companies, EveryDayHealth (www.everydayhealth.com) has a very well-structured portal targeted at providing members with reliable, quality and personalized information on health and wellness issues, with an important network of proven experts who users can directly consult - experts who participate together with other recognized sources in the inclusion of content on the site. The different content on health and self-control tools it gathers in detail are easily adaptable to the profile of each user: information, news, advice, publications, research results, etc., and the site is easy to browse. There is very clear information on the

site's strategy and the professional background of its managers and collaborators.

HEALTHCENTRALNW (Social Networking Site. USA)

This site (www.thehealthcentralnetwork.com) is one of the three/four big ones that compete in the US market. In particular, HealthCentralNetwork integrates 35 independent portals, each devoted to the health or wellness-related topics it supports. The site tries to compete via the quality, reliable information it provides, to which end it has important strategic agreements with different partners. It has a large number of publications and multimedia documentation, as well as self-control and self-diagnosis tools which can be accessed via a broad range of segmentations. The site's management team comprises health professionals and people from the advertising and communications sector.

iVILLAGE (Social Networking Site. USA)

iVillage (www.ivillage.com) is a social networking site aimed at providing a communication environment for women. It has eight spaces on different health-related topics. Within each, and in particular the one concerning health, there is information on a great many aspects, which is well-structured. There are also self-testing, self-monitoring and survey tools. It also has a tool to consult with health experts.

PATIENTSLIKEME (Social Networking Site. USA)

This site (www.patientslikeme.com) focuses on a small number of diseases (13) and has powerful graphic tools for controlling and monitoring treatments and symptoms. It aids in the exchange of experiences, ways to learn more about the diseases and how to use medicines. It has one of the biggest databanks on the diseases it covers because it converts experiences into data. Its business model is based on selling its anonymous data to interested investors and organizations. It has tools to carry out trials and a team (including R&D) which draws conclusions based on patient data.

REVOLUTIONHEALTH (Social Networking Site. USA)

This site (www.revolutionhealth.com) is aimed at achieving a better level of public education as a way of reducing general health costs. It also offers information to users on health-sector products and services, tools and software. One aspect that makes the site stand out is that it offers comparative information on the quality and prices of these services, fostering a tool to achieve potential savings on health spending for the public. Some of the content provided is supported on other health sites of the same Group to achieve synergies and it has a great many health tools and trackers, as well as help in webpage generation.

SERMO (Social Networking Site. USA)

SERMO (www.sermo.com) is a social networking site for medical professionals. It is a platform for exchanging experiences, opinions, articles and trends, and for exercising joint positions, e.g. against the Administration. This forum provides information on discoveries and their problems before they become official. Although the content is used anonymously, it is necessary to register and identify yourself via your doctor's licence number. The business model is based on the sale of the results of surveys and the exchange of experiences to investors and organizations in the health industry, promoting the participation of professionals by paying for the services of the most important ones.

VI.VU (Social Networking Site. Spain)

This site (www.vi.vu) enables the exchange of experiences between patients and other people in their environment, and between professionals. This means you can consult professionals and locate them. There are tools to create specific networks which also enable environments for private members to offer a platform to set up networks of associations and foundations. It was developed with the support of the National Programme for Health Technologies.

WEBMD (Social Networking Site. USA)

WebMD (www.webmd.com) is one of the most important health-related social networking sites in the US. Via different portals, it offers proven information on health and healthcare, symptoms, diagnoses, pharmaceutical information, information from health professionals, tips, etc. Its users are patients and consumers in general, to whom it provides education, and other people who help manage health and wellness, via self-help tools, doctors and other health sector professionals who access its publications and reference information, enabling the publication of articles and the exchange of opinions with colleagues, businesses and societies, constituting a contact point that makes it possible to analyze and manage the range of health plans on offer. It is one of the best-accredited health-related social networks from the viewpoint of its quality and code of conduct.

YAHOOGROUPS (Social Networking Site. USA)

YahooGroups (www.yahogroups.com) in Spain is formed of 16 virtual online communities, one of which focuses on health, configured around an email-management application. The community aimed at health aspects can be considered a social networking site because it uses the power of Yahoo tools but with a general and common approach with other virtual communities. It lacks the specific facilities found on other sites devoted to health, such as the participation of sector professionals via articles, publications and consultations. The Yahoo Health Groups community in Spain comprises a large number of forums generated by the members and structured in a weak fashion.

FORUMCLINIC (Portal. SPAIN)

This Spanish portal (www.forumclinic.org) incorporates documentation on 11 diseases (fields) in a rigorous and useful structuring, with the goal of contributing to a better positioning of the general public and patients in particular when it comes to making health-related decisions. The portal is managed by health sector professionals and the documentation they contribute includes

information on the diseases, pathologies, guides, articles, impacts, consequences and curative and preventive treatments. It provides professionals with tools for knowledge transfers about different fields, around each one of which a significant amount of documentation is generated. The portal has a Scientific and Technical Committee.

HEALTHCARE (Portal. USA)

HealthCare (www.healthcare.com) is an information portal on healthcare services and associated providers, basically regarding plans, health insurance and insurance companies. For these services there are simulators so that, depending on the features of the user, costs can be assessed. It also has information on other health and wellness-related aspects such as diseases, treatments and self-monitoring tools.

HEALTHCARESCOOP (Portal. USA)

The goal of this online community (www.thehealthcarescoop.com) is to provide the public, considered consumers, with reliable information on all topics relating to health services: health professionals, clinics, hospitals, conditions, etc., helping them in decision-making and attempting to promote improved quality and transparency among service providers. It aims to provide the public with information similar to that which exists for commodities such as electronic goods or automobiles.

ORGANIZEDWISDOM (Portal. USA)

This site (www.organizedwisdom.com) offers a browser service on health and wellness topics which complements the facilities of traditional browsers. To that end it contributes human intelligence to the search process, organizing, prioritizing and classifying non-structured information from the Web and eliminating that which has no value. This work translates into a 'Wisdom Card' for each topic, which includes the 10 best-related sites, selected by experts and members, as well as related information. In addition to the expert collaborators, a large number of freelancers work for the organization, so it has a very good methodology to guide them in their work.

RELIEFINSITE (Portal. Hungary)

This Hungarian site (www.reliefinsite.com) focuses on pain management and has its own patented tool to permit its daily control. The tool includes powerful graphic facilities to locate and monitor pain, symptomatology, treatment, etc. It can act as a carer, providing guidelines and alerts in line with the information provided by patients, and also offers an interactive pain-management tool which users pay for. There are also facilities for telephone access using voice technology.

WEBPACIENTES (Portal. SPAIN)

WebPacientes (www.webpacientes.org) is the communication path of the Spanish Forum of Patient Associations, whose goal is to promote the appropriate representation of organizations that defend the rights of Spanish patients. It is a joint initiative of the Josep Laporte Library Fund and MSD and comprises a management centre that promotes knowledge about the activities of patient associations.

DIABETESMINE (Blog. USA)

This blog (www.diabetesmine.com) involves housing knowledge on diabetes, integrating easily accessible information and is much more user-friendly than the information contained in professional articles available online. The content is included by invitation of the blog owner and its success has led her to include publicity at the request of advertisers and to enrich the blog with a great number of publications and content on the disease.

ONCOCHAT (Chat. USA)

OncoChat (www.oncochat.org) is an application that permits direct interaction via chats between cancer patients and people in their environment (family members, friends, carers, etc.). It aims to complement the power of the Internet in terms of documentation on cancer, with a real-time forum in which patients can communicate immediately, find help and emotional support. It permits public and private conversations.

FLUWIKI (Wiki. USA)

This site (www.fluwiki.info) aims to help alleviate the effects of flu pandemics, trying to include all possible information about them in a collaborative fashion and integrating information provided by users via the publication of available information, with the conviction that a fully collaborative contribution can give rise to a complementary perspective to that of the official organizations responsible for managing flu. It includes basic scientific information, information on flu, its prevention, progress, legal aspects and a guide on how to publish collaborative information.

According to an assessment by Compete.com, these sites together receive over 30 million different visitors per month and more than 48 million hits per month, making them a very significant sample around which diverse business models (explained further on) are being configured which is, at the American level, giving rise to strong competition.

Report Content

The report that results from the study is comprised of the chapters mentioned below, together with a brief summary of their content (as well as the Introduction, which constitutes Chapter 1).

Chapter 2. Study Characterization and Sphere of Application. The aim is to focus on the analysis developed in subsequent sections and delimit the scope of the report, normalizing the terminology used in the sphere of online health and wellness.

Chapter 3. Classification of Health and Wellness Social Networks Using Three Criteria. This section is devoted to classifying the social networking sites on the Internet that are the object of this study, based on the following three criteria:

USES AND SERVICES

- Emotional support and exchange of information.

- Medical professionals' opinions
- Self-monitoring tools
- Access to clinical trials

USERS

- Patients: healthy, recently diagnosed, chronic
- Health professionals
- Environment: Relatives, carers, friends

USER ACCESS

- TV
- PC
- MV (GSM, GPRS, UMTS, HSDPA)
- PDA

This makes it possible to establish a suitable structuring of the analysis of each selected site done in Chapter 5. It also includes a series of quantitative data on the use of the sites from each of the three perspectives.

Chapter 4. Quality Guarantee of Content, Usability and Accessibility. Given the sensitive information handled on Health and Wellness Social Networks, nobody can be unaware of the importance of having quality and reliable certification and accreditation bodies that make it possible to ensure the sites are being managed properly. This chapter addresses this, together with aspects of usability and accessibility.

HEALTH SOCIAL NETWORK QUALITY

CODES OF CONDUCT (principles, standards, guides, recommendations)	<ul style="list-style-type: none"> - EHealth Code of Ethics from the IHC - AMA (American Medical Association)
QUALITY SEALS	<ul style="list-style-type: none"> - Health on the Net Foundation (HON) - Hi-Ethics - Web Médica Acreditada (WMA)
USER GUIDES	<ul style="list-style-type: none"> - DISCERN - IQ Tool - QUICK - NETSCORING
FILTERS	<ul style="list-style-type: none"> - OMNI (Organising Medical Networked Information) - MedHUNT, - WMA Google Search
CERTIFICATION BY THIRD PARTIES	<ul style="list-style-type: none"> - MEDCERTAIN (or MEDCIRCLE) - URAC - NHS Direct Online - TNO QMIC
ACCESSIBILITY & USABILITY	<ul style="list-style-type: none"> - Web Accessibility Initiative (WAI) - AENOR -UNE Standard 139803:2004 - Section 508, US Rehabilitation Act

Chapter 5. Functional Analysis of Health and Wellness Online Social Networks. Chapter 5 collects the criteria by which the 19 social networks which are analyzed individually in the chapter were selected. The aim of this section is to perform, within the spheres of the selected sites, an analysis of their functional features in line with the classification explained in preceding chapters, elaborated on with other features that appeared during the analysis, attempting to provide the results with a comparative

structure and focusing them so they may be of maximum interest both from a didactic viewpoint and from the perspective of potential users.

Chapter 6. Best Practice Cases. This chapter summarizes the best practices identified in the analysis of the selected sites performed in the previous chapter.

Chapter 7. Trends. This chapter involves identifying foreseeable ways social networks

in general and those relating to Health and Wellness will evolve in the future.

Chapter 8. Conclusions and Recommendations. Finally, this chapter collects the main results that arose from the analysis of the Health and Wellness Social Networks and identifies the value they bring, their utility and the relevance of their application.

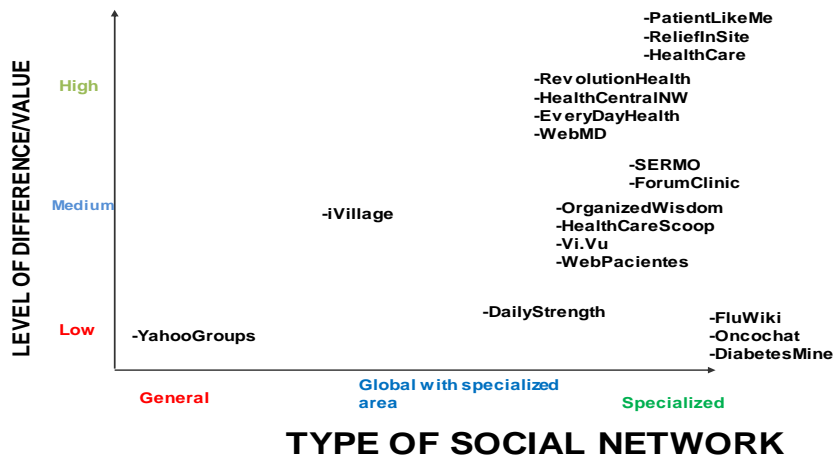
Best Practices

There are different fields from which we identified the best practices that emerged in the analysis of Health and Wellness Social Networks in general and those of the 19

selected significant ones, all of which are the object of this present study:

- Approach of the Health and Wellness Social Network.** Basically we found three different approaches: general, global with specialized areas, and specialized. There is no doubt that the Health and Wellness Social Networks that add the most value are those in the specialized field. These sites provide powerful tools for disease management, such as the case of PatientsLikeMe, and equip patients with the best support teams and most specialized publications.

DIFFERENTIATION OF SOCIAL NETWORKS BY TYPE



- Scope of Information.** As a result of the analysis performed, the Health and Wellness Social Networks, or the areas devoted to health and wellness on networking sites that include other fields, can be classified as: Universal, Limited Scope, Single Issue or Mixed.

From the analysis of the social networks that are the object of the study, from the point of view of their scope we found that the best practices emerge in those with a greater scope, where the large volume of information handled imposes an optimal structuring of their content (which

includes a large number of possible aspects to address, basically diseases, and different perspectives to consider, such as symptomatology, conditions, medicines...).

Social networks should permit both easy browsing and searching as well as a good integration of related topics, including access to associated tools, forums, consultations with experts...all of this bearing in mind not just the volume of information handled, as already mentioned, but also the potential status of a large part of the members, i.e., patients, whose faculties could be

undermined in certain circumstances as a result of their situation.

- **Business Models.** Leaving aside sites without a business approach, usually smaller ones that do not include all the features associated with social networks such as Oncochat or FluWiki, we found the following business models:

- Based exclusively on advertising.
- Funded by private investors, mainly organizations in the pharmaceutical and health sector.
- Funded by sponsors/health sector providers.
- Funded by/integrated in foundations/non-profit organizations.
- Funded by the sale of services: data from member experiences, survey or trial results, consultations, etc.

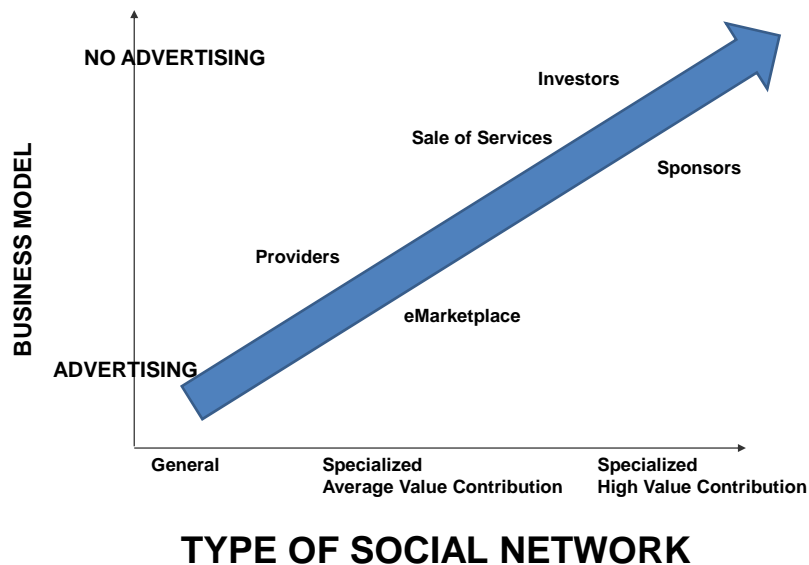
- eMarketplace. Some social networks include e-marketplace facilities focused on health and pharmaceutical products as a source of revenue.

- Mixed models. These include a mixture of some of the possibilities mentioned above.

Although mixed models were the most common, there was always a prevalence of some of the abovementioned possibilities, mainly based on advertising, although sale of data is beginning to generate revenue in the US.

Around 70% of the sites analyzed were totally or partially funded by advertising and less than 15% said they have no advertising-based model. There was a correlation between type of social network from the viewpoint of its typology and business model, attracting members or advertisers in line with its quality and content, closely linked with the number of users.

BUSINESS MODELS IN LINE WITH TYPE OF SOCIAL NETWORK



- **Social Networking Site Services.** Even when they met the features of social networks, not all included them to the same extent.

In relation to aspects associated with user-profile management, it was enough for them to be in line with the network's goals, in the sense that the user was able to identify the value of having joined the network, preventing the idea that they could be used for other purposes. They should not be requested more than necessary or less for them to impede the suitable functioning of the tool.

With respect to contact management, appropriate management is a topic of greater interest not just because of the need to provide users with the ability to establish privacy limits versus the convenience of their own experiences being shared with others to the extent desired, but also for the sensitivity of the aspects addressed on the networks concerned or the right of users to select the person from whom they wish to request support and aid at any time and in line with their condition.

Communication and Interaction Mechanisms Among Users. The analysis did not show that an abundance of communication facilities on the networks contribute as much to their success as their content, the possibility of help by the professionals involved, or their quality and reliability. However, the trend is to include the maximum number of them possible.

There were complementary communication mechanisms in addition to the basic ones, such as visitors' books, newspapers and the possibility of sending virtual hugs, and while it is true that they can provide additional information and emotional connotations, they did not appear to be decisive from the viewpoint of the provision of value of the network.

What does seem to be of interest was the ability to assess the relevance of the

information provided by members and the number of members, which shows users the background of possible contacts. This is in keeping with the trend observed among users to prefer quality relations over volume of contacts.

- **Facilities and Tools.** In addition to the possible focuses and approaches of Health and Wellness Social Networks and the greater or lesser availability of the features that configure them, we identified a high number of additional potential facilities and tools on the sites analyzed which undoubtedly contribute to their differentiation and provision of value. All of these are good practices that provide differentiating elements and it was important to analyze the opportunity to integrate them in each particular case. This was done by assessing the commitment of the provision of value/cost of the opportunity. There are many facilities associated to user conditions, such as:

- Consultations with experts in real time or otherwise.
- Management tools for aspects related to diseases (symptomatology, treatments, etc.) such as the case of PatientsLikeMe which transforms experiences into data, or the pain management tools on ReliefInSite.
- Self-diagnosis tools, self-monitoring tools, health tools and trackers.
- Application for carrying out trials and research.
- Tools for carers.
- Protocol monitoring for particular symptoms and conditions.

There were also other series of tools and facilities which were identified in the study associated to the management of

the network itself and the provision of differentiating capabilities.

- **Content.** Logically, content is another differentiating factor of social networks, and the ones below may be considered common, but they can be differentiated in terms of approach, quality, ease of understanding, source reliability, or format (textual, video, photo)...
 - Publications and articles on diseases written by professionals
 - Collaborative documentation
 - Guides on diseases
 - Action protocols
 - Courses, conferences and other events aimed at educating patients, professionals or the general public
 - Collateral information on Health and Disease, as well as legal information.
- **Access.** Throughout the analysis of the social networks selected we were only able to identify the possibility of access other than PC-based access in two cases. One was WebMD, which has a specific application for access via iPhone, and the other was ReliefInSite, which permits access to particular applications via the telephone, using voice technology.
- **Managers and Management Bodies.** Throughout the analysis of the different social networks we found, as an example of a good practice, the availability on the networks of references to their managers, which set out their experience and responsibilities, as well as management bodies. This undoubtedly helps make them more transparent and promotes their capabilities. The latter includes management boards, technical committees, publishing houses, R&D teams and advisory committees.
- **Quality and Accessibility.** Similarly, it is also desirable that the networks meet,

with the greatest rigour possible, the general criteria of webpage design to ensure the quality of their content and access to it. Although it is not essential, it is considered a very good idea to have certification of these aspects of security and reliability provided by an accredited body.

From the perspective of accessibility and usability we should remember that as well as facilitating general access to people, independently of their features, the networks should allow access via channels other than the traditional PC (mobile phone, PDA, TV, etc.). That is why there are currently certification mechanisms for websites which ensure their accessibility and which it is recommendable that these types of networks include.

Without arriving at certification in any of the aspects dealt with, it is recommendable to at least include a declaration of commitment to these aspects (security, reliability, accessibility, etc.).

Trends

The Internet has been used as a support for the establishment and development of social networks for less than five years but in that time it has promoted an extraordinary development of them, to the extent that we can speak of a whole phenomenon in which millions of Internet users connect every day, whether in their work or free time – a phenomenon which has taken place in every country to a greater or lesser extent.

We should now ask whether this evolution of the past few years will continue in the immediate future or whether it is going to taper off or slow down, as has happened with other applications such as those relating to virtual worlds (Second Life), where spectacular growth was followed by significant decline.

In this case, the answer is yes it will continue. Internet and Web evolution will be unquestionably marked in coming years by their social character. This means it will not

be consolidated but that the development of social networks in general and health-related ones in particular will rise, particularly because they present a number of distinctive aspects that will provide them with greater value in a social web environment like the one that is coming.

The following table shows the main ways this change of Internet paradigm is manifesting itself:

Shift of the Paradigm	
Services/Data	People
Web	Social web
Closed	Open
Heavy	Light
Revenue	Friendly relations

The latest conference on Health 2.0 held in San Francisco included a talk about the eight trends considered to be set to lead the evolution in this field. The first referred to the growth of social networks. Of note at the conference was the presence of an astonishing number of start-ups focused on the creation of communities for doctors, patients, carers and others that were capable of building sustainable business models, particularly in the current economic downturn.

The development of health-related social networks will be supported on what is called the 'Four Cs', i.e., communication, collaboration, community and content, which will lead us into an unprecedented era of information sharing and collaboration between groups, enabling us to work together using these new tools. This is related to another important aspect, which is that social networks are going to make an important contribution to conferring much more power on patients via access to information on their diseases. This involves a shift of power in the doctor-patient relationship because to date it was the doctor who knew more, and opens

the door to business opportunities for sites dedicated to patient education.

Once we agree that over the coming years we are going to witness a growth in these networks, the next thing is to ask what the health-related social networks of the future will be like. In this regard, there are a number of aspects that will determine their evolution:

- **Technological Evolution**

The ongoing convergence of online SW and other services on mobile platforms (smart phones) and domestic platforms (TV) and the appearance of technologies that will affect products and services are going to change the environment in which developers and users operate. The iPhone is an obvious recent example.

The convergence of platforms means we will be able to access applications which until now have only been accessed via a platform such as a TV, radio, PC or mobile phone, from any of them and in a new combination of products and services.

If we bear in mind that communication is at the basis of all social networks, communication facilities such as the possibility of uploading videos or video messages can be important. In fact, some of today's networks already include them. Also of note will be the incorporation of instant anonymous web-based messaging services which permit direct one-to-one communication between patients without additional downloads. Other trends of future evolution may arise from the incorporation of artificial-intelligence techniques that permit computers to perform tasks that are simple for humans, such as recognizing faces or models.

A fundamental aspect in this area of communication is mobility. The proliferation of mobile phones is enabling users to manage their social relations via a portable channel which lets them connect with anybody. But for now there are still a number of limitations for mobile social networks when it comes to seeing all their contacts at once, for example on a social graph and, more importantly in this context, they do not make it possible to

see how the contacts are interconnected. Although this requisite is more important on general social networking sites like Facebook or Twitter, the case of health-related social networks should not be underestimated.

The upsurge in new applications for mobile phones, e.g., localization-based services and mobile-phone Internet access, will make the mobile phone the preferred method for accessing the Internet in the future and therefore accessing online social networks.

- **New Internet Facilities**

Other innovations will arise from the evolution already taking place in the Internet itself. Of these, the ones that will impact social networks the most are:

- Greater functionality, via enriched Internet applications, which are going to significantly change the way people interact.

- The semantic web, which involves the use of a set of formal rules to express the meaning of data, the properties of objects and the relations that exist between them. One example: if we were to presently make the following consultation regarding Alzheimer's Disease, i.e., "What proteins are involved in signal transduction and are related with pyramidal neurone?", with a traditional browser we would find 223,000 references but 0 results. With semantic browsers that make it possible to link related health data, we would find only 32 references but they would all be valid.

- The improvement of user interfaces and the trend towards their personalization.

- **Network Interoperability**

One point on which there already seems to be consensus is the need to permit users to connect and share content with users of other platforms and to support developers with simpler ways to roll out system applications. Although there are different approaches, it seems clear that we will move towards portability, compatibility and interoperability via the use of diverse technologies that already exist.

- **Collaborative Browsers**

The combination of the semantic web and the interoperability of networks is leading to a change in browsers, too. Social networks are changing the meaning and orientation in the search for answers, attempting to in some way trace their importance by the contributions that have made it possible to create this information and the type of consultations received. The aim is to provide browsers with intelligence on the quality and reliability of information on the basis of their sources. The solution being investigated is emerging with search engines that work in collaboration.

- **Business Models**

Social networks have attracted an enormous amount of money both from venture capital enterprises and corporate budgets, particularly in the media industry. The evolution of these networks involves the existence of sustainable business models. Currently the majority of networks are maintained through advertising revenue, although in some very specific cases there are also models involving user subscription. However, the enormous potential of information associated with these networks and the strength of patient communities will lead to the development of new models, some already up and running on some networks such as ones that focus on marketing information on experiences with new drugs or carrying out clinical experiments.

These models require a particular audience for the networks to survive, in terms both of size and level of involvement or participation, although there are also successful models associated with content purchases.

In order to survive, the proliferation of social networks will require the provision of value that makes them stand out from other networks by a rise in functionality (in all likelihood in many cases they will combine social networks and online services of teleassistance, telemonitoring and telediagnosis, boosting the utility both of these services and of the social networks themselves) or via specialization, which will

predictably augment the number of niche communities.

- **Security**

As commented above, the interconnection of social networks will provide significant value, but it will be necessary to ensure aspects of security and confidentiality of the information users upload onto the network. The issue of identifying individuals must be resolved, because it is important that a person can be monitored via the social network but that his/her identity is kept anonymous, and also it is necessary to resolve access to the information the user uploads onto each social network to which he/she belongs, so he/she can decide, within a connected web environment, which information is accessed and by whom.

- **Vertical Social Networks**

Another trend spoken of for coming years is the proliferation of vertical social networks, with the participation of diverse levels. In this regard it is perfectly logical to think that if to date social networks have been a meeting place between private users exclusively, there is nothing to say they won't evolve towards a meeting place of people with businesses and public administrations. This is already occurring in the case of specialized social networks, such as health-related ones.

- **Behavioural Habits**

The social networks of the future should collect behavioural models that will become more generalized as they grow. Some of these models are:

- Multiplicity and diversity. Social networks should permit ever-increasing inferior levels of segmentation, adapting to the specificities of users. As they become increasingly dominant, it will be ever more important to show social networks in accordance with user context. Geographical sphere will be an important element of segmentation. This segmentation of groups will be an entry barrier to new social networks.

- Also, the proliferation of networks should be matched with the possibility of clients

adding RSS entries on important discussions to show on affiliated websites.

- Quality and the fight against fraud. Inevitably, fraud is a risk present in the social-network environment. In the case of health and wellness networks, this risk is greater, not only because of the important economic incentives for certain treatments, medicines or hospitals centres to have a good reputation or very favourable statistics among patients, but also for the effect it could have on the ill. That is why quality procedures and certifications, many of which already exist, should become more widespread.

It is also important to mention that a number of applications are beginning to appear which are targeted at analyzing feelings that make it possible to discover attitudes on particular aspects. This makes it possible to select a topic, e.g., a hospital, medicine, etc., and to check in real time whether it is being spoken of in good or bad terms. This would be a very powerful tool for pharmaceutical companies, insurance brokers, etc.

In short, to paraphrase Werner von Siemens, we can say that do not know what the future will hold but we can invent it. We do not know what the health social networks of the future will be like, but starting from what we are seeing now we can anticipate that they will grow in number, that those of a vertical nature will prevail and that they will incorporate new facilities associated with medical applications, consultations with specialists, etc. All of this will be in an environment characterized by the connections between different social networks, the semantic web, advanced user interfaces and mobility.

Conclusions and Recommendations

Throughout this report we were able to observe information referring to a growing facet of the Information Society. It involves a new stage in the development of the IS, in which *health and wellness information is made accessible to users*, in different formats, so that it may be *shared by all users*.

We saw a number of differential facts:

- It involves information on user health.
- It is users who are providing the information.
- The information is shared among everyone involved.

All of this is done on communication platforms based on Web 2.0 technologies known as Online Social Networks.

In this section we summarize some of the most noteworthy conclusions of the report:

C1. The first conclusion is the confirmation that we are witnessing the birth of a phenomenon, i.e., health and wellness online social networks, which are expected to have a great impact on the treatment of medical information, the relationship between the different agents in the health system and probably society in general.

C2. The second general conclusion from this study is that the number of people performing activities on health and healthcare-related social networks is growing, boosted by the global rise of social networks with general content.

C3. This study highlights that the Internet is changing our view of health and healthcare in general. Social networks dedicated to health are appearing as an intermediate link between mere sources of information on the Internet (websites, wikis, blogs, etc.) and traditional forms of the doctor-patient relationship. Appropriate use of this new reality will make it possible to make a number of healthcare processes more efficient.

C4. A fourth conclusion is drawn from the fact that networks that provide the most value are specialized with regards focus, with a great scope in terms of the volume of information and which, in terms of usability, are easy to use.

Despite the positive conclusions indicated above, we detected other conclusions that could present important limitations and

barriers to online social networks reaching their potential capacity in the short term:

C5. Working with such sensitive content as that which relates to health requires quality parameters for the information and a more precise guarantee of confidentiality than those of traditional social networks.

C6. It is necessary to appreciably improve a series of aspects which are limiting the access and use of social networks to large groups of users:

- a. More user-friendly interfaces than the keyboard and mouse (e.g., touch screens).
- b. Simpler user terminals for the elderly or handicapped (PC and mobile platforms).
- c. Sustainable business models to ensure the maintenance and quality of the platforms.
- d. The use of social networks by professionals, businesses and public administrations (in the same way that they already use older Internet services such as email and web).

To make the most of and boost the positive conclusions and overcome the negative conclusions of this study, we would make the following recommendations:

R1. It is necessary for the managers, members and designers of health systems to incorporate this new instrument (online social networks) in their care plans.

R2. With respect to business models, the evolution of these networks involves the existence of sustainable business models.

R3. To launch a possible new social network it will be necessary to bear in mind that to survive it will have to provide value that is different to that of other networks. This value may come from specialization in new niches or in the potential afforded by new technologies.

R4. Finally, it is important to underline that the challenge will be to transform the opportunities that the rise in health-related online social networks offer into value. These

opportunities are aimed both at improving patient care and developing the opportunity for new business forms parallel to the ones that already exist within the more traditional care model.

Sanitas Chair

One of the activities undertaken by the Sanitas Chair is focused on having an Observatory on Information and Communication Technologies for Health and Quality of Life.

This Observatory has a multidisciplinary vocation and aims to cover a very wide panorama on any issue related with the application of ICTs to any aspect of health and wellness. With the Observatory, the Chair aims to collect information and prepare periodic reports on the level of penetration of ICTs.

In turn, the Observatory has considered, among other tasks, that the preparation of specific studies on particular issues within the framework of health-related ICTs can be useful for professionals interested in the Observatory.

This is the sphere in which the present surveillance study was developed and which, together with the executive summary, is available at the Sanitas Chair website (www.catedrasanitas.org).