Monographs of
the Víctor Grífols 20
i Lucas Foundation

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Ethical challenges of e-health

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PRESENTATION

The President of the United States, Barack Obama, has proposed creating a public health service in the United States. The programme, which seeks to correct this glaring deficiency in the world's most powerful country, includes e-health as a key element, confirming the significance of this technological option in addressing the challenges faced by universal health care in the 21st century.

The Pew Research Center[a] in the United States, which analyzes public opinion and public attitudes, has been carrying out the *Pew Internet & American Life Project*[b]. This is a long-term study which considers the impact of the emergence of the internet on all of our daily lives, and looks at the significant changes brought about by the use of this technology and this vehicle for accessing knowledge. In 2005 an early report on *Health Information Online*[c] identified health as one of the sectors which would change most in the coming decade, together with publishing, the media, education and government. It also highlighted the fact that the vast majority of internet users in the United States use the web to access health information. Naturally enough, this sort of search has rapidly been extended to all sorts of online services, such as the sale of drugs, diagnostic tests, and first, second and third medical opinions. Nobody can ignore both the benefits and the drawbacks (even the dangers) which may arise from the fact that this method of managing health resources is becoming increasingly common in societies where the level of education varies widely.

A good example of the profound changes which are occurring in this regard comes from a study published in the journal *Atención Primaria*[d] which found

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[a] http://pewresearch.org/

[b] http://www.pewinternet.org/

[c] http://www.pewinternet.org/topics/Health.aspx

[d] Mira Solves, José Joaquín; Llinás Santacreu, Gilberto; Lorenzo Martínez, Susana; Aibar Remón, Carlos. «Uso de Internet por médicos de primaria y hospitales y percepción de cómo influye en su relación con los pacientes». *Atención Primaria; 41(6):308–314;* June 2009.

that patients frequently ask doctors about information they have obtained from the internet. It revealed that 96% of doctors have received questions from patients who had checked the internet for information or obtained further information about their diagnosis which they then wanted to discuss with their physician. As a result, 31% of doctors believe that the internet complicates their relationship with their patients and undermines their credibility.

We should also remember that e-health affects all those aspects of health care which rely on information and communication technologies, such as electronic medical files, telemedicine (physical and psychological tests which do not require a face-to-face encounter), the dissemination of information, and virtual healthcare teams (professionals who work together and share information about patients as members of digital teams). In Spain it is estimated that over 40% of people use the internet to look for health information, making it a major focus of innovation and an area with massive potential for the future. However, it should also be noted that there have been very few studies of its influence and impact to date.

The Víctor Grífols i Lucas Foundation[e] and the Scientific Communication Research Centre of the Pompeu Fabra University[f] organized a discussion day under the heading «The ethical challenges of e-health», the results of which are presented here. We hope this will encourage further debate and contributions from those experts from across the health industry who are involved with this major tool which, if used appropriately, offers the potential to improve both individual and collective health.

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Vladimir de Semir
Director of the Scientific Communication Research Centre,
Pompeu Fabra University

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[e] www.fundaciogrifols.org/

[f] www.upf.edu/occ

Ethical challenges of e-health

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In just a few decades the expansion of the internet has given rise to significant changes in the field of health. These transformations have had an impact not only on health information, but also on health care itself, on the relationships between different groups, on the management and organization of health systems, and on almost every sphere one could imagine.

The scale of the change is such that it is hard to believe it has occurred in such a short space of time. As a result, it is not only the young who sometimes find it hard to believe that the internet has not always been with us; adults of all ages often struggle to recall what life was like without it. How did we manage to find information, exchange documents or images, call a meeting, organize a trip or just communicate with someone on the other side of the world without incurring a massive phone bill?

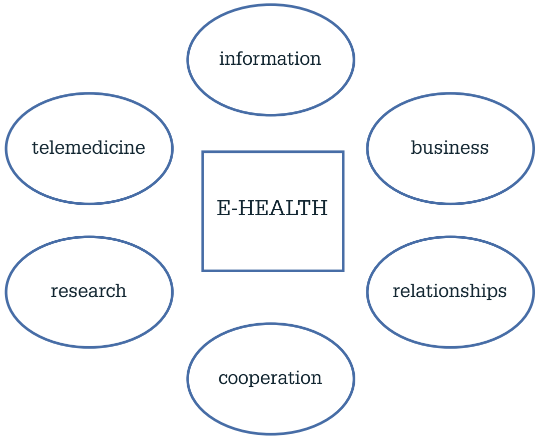
Another example is to be found in terminology. In the health field, terms such as electronic health card, shared medical records, telemonitoring, health 2.0 or «e-health» itself abound in articles, reports, conferences and web-based resources of all types. As with the internet itself, the timeframe within which these terms were created and have entered professional jargon has been remarkably short. Indeed, new terms appear with such breathtaking speed that scarcely have we begun to grasp the meaning of one concept than another appears on the scene, demanding renewed efforts of comprehension and recall.

The term «e-health» was perhaps one of the earliest to be coined, and it is undoubtedly one of the most frequent. Indeed, it has been in use for such a long time (if we compare it to how recently the internet became part of the general landscape) that one might almost expect the concept to have become obsolete. However, it appears to have resisted the pressures of time and continues to be the best way of encapsulating the relationship between the health sector (in the widest sense) and the vast range of electronic resources which constitute the internet.

From an ethical perspective, the development of e-health raises a lot of questions, because a single process affects –or has the potential to affect– all sorts of different areas. The right to information, the right to health, and the right to privacy are the most obvious examples, but there are many more ethical issues we could identify.

While it is therefore essential to consider carefully which are the principal challenges posed by the expansion of e-health, it is also vital that we address this in a clearly defined manner, with reference to specific environments or issues. For that reason, in this document we will consider six key dimensions of e-health, each of which has its own characteristics, offers specific opportunities and poses particular ethical challenges. These six dimensions are identified in the diagram below. However, it should be noted that these are not independent or separate but are instead closely interlinked, and the boundaries between them are not always easy to identify.

Dimensions of e-health



For each of these six dimensions of e-health we will review what they mean, will describe the current situation, give some examples, and analyze some of the ethical issues associated with them.

Although this document is based primarily on the situation in Catalonia and the rest of Spain, many of the examples and applications it considers are drawn from other areas or are international or global in scope.

1. Information

Of all the possible applications of the internet to the health sphere, searching for information is clearly the most frequent. In common with other European countries, the use of the internet to find information is very frequent in Spain. The following figures give some idea of this. According to a survey by the National Institute for Statistics, in 2008, 51% of Spanish homes had access to the internet.[1] Of these, according to the same survey, more than 17 million were «frequent users». A survey conducted by Google and presented in 2008[2] concluded that 71% of internet users in Spain said they used it to find out about health issues, with the main areas in which they sought information being common illnesses, complaints of the digestive system, nutrition, beauty and aesthetics, family planning and mental health.

In Catalonia, we should mention the study by Manuel Castells, Francisco Lupiáñez, Francesc Saigí and Josefina Sánchez within the framework of Projecte Internet Catalunya (PIC) of the Open University of Catalonia (UOC), regarding how people use the internet to explore health issues[3]. This research was based on a range of tools (surveys, in-depth interviews, focus groups, etc.) and provides a thorough description of the situation in Catalonia. Furthermore, many of the results can be extrapolated to other societies. In this working paper we will be referring to this study frequently, both because of its rigorous nature and because it covers a lot of the issues we are considering here.

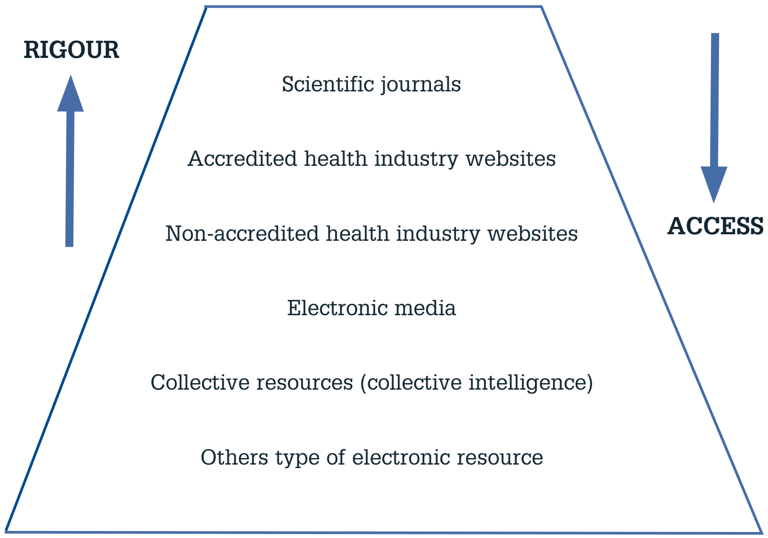
One of the results observed in the PIC study was that users searched for information on issues regarding food and dietary problems (45.5%); fitness and physical exercise (43.9%); alternative therapies (28.4%); medical insurance (26.3%); medical or health products (glasses, hearing aids, crutches, prostheses) (22.4%). In addition, 47.6% consulted sites linked to patients' associations and support groups, although their aim was to find emotional support rather than information.

Regarding frequency of use, the same study concluded that 45% of users look for health information less than once a month, 25% more than once a week, and only 7.5% do so on a daily basis (although it should be noted that approximately 80% of these were health professionals). It should be noted that, although the volume of users looking for health information on the internet appears from this survey to be quite high, the percentage who used it in an attempt to diagnose their own health problems was much lower (12.2% of those surveyed), as was the proportion of users who attempted to treat a health problem on the basis of information from the internet (10.8%). It therefore appears that users consider the internet to be useful and practical but are aware that it does not replace professional doctors.

This touches on one of the key questions in the e-health debate: the issue of whether internet-based resources replace doctors as a source of information. In fact, it is clear from the PIC report that this is not happening, and that health professionals continue to play a key role in providing information about health. However, the situation is a complex one. Patients search for information on the internet and, if they can, they discuss it with their doctors. Doctors, for their part, tend not to be very keen on encouraging patients to look for information on the internet. Why is it that medical professionals, who use the internet to find useful information on a daily basis, do not advise their patients to do likewise? The possible fear of being rendered redundant (or of losing some of their authority) may be one motive, but there are probably far more important reasons. The main concern tends to be that the patient –in principle someone who lacks medical knowledge– will be unable to distinguish between information which is rigorous, objective and useful, and information which may be inaccurate, harmful and misleading.

The following diagram orders the information available on the internet on the basis of the level of review. The information sources at the top of the pyramid are subject to very thorough control and review processes while the sources at the base of the pyramid are not.

Information pyramid



Information with a stronger evidence base and probably of a higher quality[a] is shown at the top of the pyramid, while the information at the bottom is likely to have a weaker evidence base and be of lower quality. However, the majority of peer-reviewed articles published in scientific journals –in other words, most of the top level of the pyramid– would be of no use whatsoever not just to the layperson but to anyone who lacks knowledge in the medical specialism to which the article refers. Although this information is of very high quality, it is of little use to patients or members of the general public. Despite this, studies show that many of the people who access these scientific articles are not medical specialists. As a result, some journals have decided they need to recognize the needs of these readers by incorporating «digested» versions of their scientific articles and other educational resources such as videos, games and discussion forums for general users. The result is the creation of spaces which, while controlled by the scientific journal, are not subject to the careful peer review process which characterizes the scientific production process.

Pages produced by the health industry (for example, those created by research centres, hospitals, professional associations, the health authorities, the pharmaceutical industry and patients' associations) can clearly provide added value on the basis of the knowledge these bodies have of the issues they are addressing. Just what impact such information has is determined both by the ethical values and professionalism of those providing it, and by their ability to ensure that the information is accessible and user-friendly. Many organizations have understood the need to provide spaces where patients, relatives, educational staff and members of the general public can participate (for example, forums, blogs, etc.). This is useful for everyone. It enables the publishers of websites to discover who the website users are, and to find out about their personal experiences, what illnesses they suffer from, what products they use etc. And it also helps users by giving them an opportunity to talk about their problems and exchange opinions.

The fact that a site has been created collectively and not by a single person or organization means that information can be reviewed, errors detected, and malpractice reported. However, the impossibility of confirming the specialist credentials of the authors, the lack of filters, and the absence of any obligation to declare conflicts of interest increase the likelihood of confusing users. Resources based on what is referred to as «collective intelligence» (wikis, social networks and other examples of web 2.0) which are at the centre of the second wave of the internet revolution, can be very useful as a

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[a] Quality is a difficult term to define. In this document, we will define it in terms of scientific rigour, checking data, transparency of information, etc. However, as Miguel Angel Mayer (director of the accredited medical website of the College of Doctors of Barcelona) pointed out in the discussion session included in this monograph, the crucial factor when it comes to accrediting the quality of websites is whether the information and services presented in them follow the same guidelines as information and services provided face to face. In other words, that advice is provided on the basis of medical knowledge.

source of health information. However, sometimes they merely reflect «collective stupidity» and facilitate the circulation of lies, rumours or biased information.

Finally, communication professionals are located at the middle of the pyramid: between collective and health sector resources. The systems which regulate good professional practice and govern daily conduct in the media also apply to electronic media, although it is more difficult to ensure that they are actually enforced in this arena. A very simple example is the electronic version of a daily newspaper. Unlike the paper version, the electronic one is updated frequently and the text must be written quickly, as soon as the news becomes known. This simple fact creates more opportunities for error[b]. But there are also other ways in which errors can get through the publisher's filters, most notably in those sections open to reader comment. These comments become a part of the article authored by the journalist, columnist or expert. It is as if readers were presented with a packet of information which may or may not be usable, and it is therefore essential for readers to be able to identify what has been written by whom and how reliable it is.

When accessing information, 90% of users employ search engines, primarily Google in Spain, although also Yahoo and MSN. The problem is that these search engines do not distinguish between information sources depending on their quality. In order to address this problem, Web Médica Acreditada has presented a tool called «WMA Google Search», a personalized Google search engine which gives users access to high quality health information from WMA-accredited websites and a selection of reliable websites.

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[b] However, the opposite is also the case. In a 2.0 environment there are also greater opportunities for correcting errors as more people are able to contribute to this process and to do so more rapidly (indeed, errors may even be corrected immediately, something which is not possible in a traditional media context).

INFORMATION. Some examples

COLLECTIVE KNOWLEDGE (*WIKIHEALTH*, ETC.)

Some collective knowledge initiatives in the field of health include:

- **WikiHealth** http://www.wikihealth.com/
  Online collaborative community (wiki) on health and wellness. The content is generated by users, who are also responsible for identifying any abuses and editing information which they consider to be inaccurate. There is no committee of experts to validate the information.
- **Wikipedia** http://en.wikipedia.org
  Wikipedia, the free, collaborative internet encyclopaedia, has a category for health-related articles which require expert review via the WikiProject Health and fitness and the Health and fitness Portal.
  Although the reliability of the information contained in Wikipedia has often been questioned, a study published in the scientific journal *Nature* in 2005 showed that Wikipedia was almost as accurate on scientific issues as the Encyclopaedia Britannica.
- **Ask Dr. Wiki** http://askdrwiki.com
  Multimedia compendium of documentation for doctors, nurses and medical students. All articles are reviewed by a committee, and contributors must provide credentials of their medical training.
- **Wiki Health Care** http://wikihealthcare.jointcommission.org/
  This is a collaborative forum sponsored by the Joint Commission, a not-for-profit organization which accredits over 15,000 organizations and health programmes in the United States. Contributors must register before they can participate.
- **GANFYD** http://www.ganfyd.org/
  With a very similar appearance to Wikipedia, GANFYD (Get A Note From Your Doctor) was created by a group of doctors and medical students in the United Kingdom.

- **Salupedia** http://www.salupedia.org/
  Virtual medical encyclopaedia based on collaboration between health professionals and users. It collects and classifies content which is already available for free but is dispersed across the internet. Health professionals (doctors, nurses, psychologists etc.) recommend content, giving users access to reliable information. The project is supported by the ITACA Institute of the Polytechnic University of Valencia.
- **Medpedia** http://www.medpedia.com/
  Interactive platform which aims to become the largest collaborative medical encyclopaedia and also enables the creation of interest-based networks. It is an initiative of Harvard Medical School, Stanford School of Medicine, Berkeley School of Public Health and the University of Michigan Medical School. Editors and creators of content must be accredited health professionals.

ACCREDITATION

- **American Accreditation HealthCare Commission**
  http://www.urac.org/ Website accreditation system in the United States based on Hi-Ethics principles, with the fundamental objective of protecting the personal data of users.
- **Health on the Net (HONCode)** http://www.hon.ch/
  International quality certification system based on a code of conduct and the accreditation of websites.
- **Proyecto Web Médica de Calidad (pWMC)**
  http://www.pwmc.org/index.htm
  Seal of quality for Spanish language health websites. Awards a seal of quality to websites on the basis of a range of criteria.
- **Web Médica Acreditada (WMA)** http://wma.comb.es
  Medical website quality programme of the Official College of Doctors of Barcelona (www.comb.cat) based on review and award of a seal to certify quality.

All these accreditation processes are free, are based on established criteria which are clearly set out on the accrediting body's website, and must be applied for by the administrators of the site to be accredited.

GUIDELINES AND QUALITY CRITERIA

Recommendations, guidelines and quality criteria to help internet users when looking for health information:

- **American Medical Association (AMA)**
  http://www.ama-assn.org/ama/pub/category/1905.html
  Guidelines containing recommendations for creating medical websites published by the AMA.
- **CISMef** (Catalogue et Index des Sites Médicaux Francophones)
  http://www.chu-rouen.fr/cismef/
  French-language catalogue of high-quality health content on the internet for professionals. Based on the Dublin Core Metadata Initiative.
- **DISCERN on line**
  http://www.discern.org.uk/
  Quality criteria for websites which provide users with a way of assessing websites which recommend treatments and diagnosis.
- **MedIEQ**
  http://www.medieq.org/
  European project, under the auspices of the General Department for Public Health and Consumer Protection, which uses metadata and web semantics techniques to assess the quality of information. Coordinating bodies include Web Médica Acreditada.
- **Intute**: Health and Life Sciences
  http://www.intute.ac.uk/healthandlifesciences/medicine/
  Catalogue of high-quality internet health resources for professionals.
- **«Ten Commandments» for users of health websites**
  http://www.guiasinfosalud.es/decalogo.html
  Spanish-language recommendations for internet users (general public and patients) promoting the responsible, safe use of health information and better communication with health professionals working in Spain's public health system.

2. Relationships

Despite the rise of Web 2.0 tools, it should be said that use of the internet as a means of communication remains a minority activity. Although most internet users consume content, creating new content or commenting on existing content is still a minority pursuit. However, the PIC report[3] mentioned earlier identified willingness on the part of users in this regard.

The use of social networks is growing daily, and there are currently estimated to be 272 million people worldwide interacting through such networks, and almost 8 million in Spain alone, according to a study[4] by Spain's data protection agency (AEPD) and the National Institute for Communication Technologies (INTECO). The social network with most members worldwide is Facebook, which has around 175 million active users[5] and is growing at a rate of 480,000 new users per day. In Spain, the most widely used network is Tuenti, with over three million active users[6]. These two networks are aimed at different publics: Tuenti is targeted at adolescents and you can only join if you receive an invite from an existing member, while Facebook is open to everyone, regardless of age. Other major social networks include LinkedIn, Xing (incorporating Neurona) and MySpace.

The use of social networks is having an impact in a wide range of fields, including health. The number of users and the upward trend has led many institutions and companies to see them as a powerful opportunity for communicating with their audiences. For example, in December 2008 Spain's Department of Health and the Consumer ran a campaign to raise awareness of condom use among adolescents on Facebook and Messenger. This was not the first time the Department of Health had used new technologies to reach a younger audience. At the start of 2008 it launched Robin, a virtual doctor who answered questions about sex and alcohol on Messenger. Although the tool was criticized for a lack of information which limited its ability to respond, the initiative was welcomed as a positive attempt to connect with a younger public, using their own channels of communication.

Social networks have multiplied communication between people throughout the world, friends of friends, relatives, supporters of a cause, fans of a singer or writer. «My friends' friends are my friends» would appear to be the slogan of these attractive, user-friendly networks. But if communication with others is positive for human beings, social networks also raise complex questions.

The main problem with social networks is the threat to data privacy. A resolution approved by the data protection authorities of 37 countries under the umbrella of the 30th International Conference of Data Protection and Privacy Commissioners held in October 2008[7] warned that the rise of these services has promoted an unprecedented level of dissemination of personal data and photographs; that the data included in social network profiles may be leaked when these are indexed by search engines; and that the HR managers of some companies investigate the profiles of job candidates. The resolution strongly advised young people not to reveal their addresses or phone numbers. The AEPD study[6] also found that social networks are the target of attacks to propagate malware including spy programs which gather information about the uses to which individual computers are put, and to obtain and exploit data from them.

Finally, social networks also raise other arguably less important issues. One of these is the disappearance of the barrier between the personal and the professional. Family photographs, conversations with friends, day to day concerns and, inevitably, information about health issues, are shared not just with family and friends but also with work colleagues and other people in the work environment. And the proliferation of applications which «request» data about the people who belong to your networks helps ensure that this mixture of the personal and the professional is insoluble and beyond the control of the individual.

A somewhat different phenomenon is that of networks created to bring together patients and doctors, or those for people suffering from a particular illness. In fact, many of these sorts of initiative do not strictly comply with the social network model as used on the internet, but refer instead to resources which enable different groups or individuals to come together in order to share experiences, opinions and advice on specific issues. Web 2.0 has enabled the appearance of platforms which make it possible to create virtual communities where doctors and patients can interact and share information, and users can evaluate the care they receive from professionals. It also opens up huge possibilities for relationships between patients, allowing people to share experiences about illnesses, learn about them and enjoy emotional support from others who have suffered the same problem. Without new technologies, establishing these relationships was far more difficult. And, of course, health professionals also see the social web (Web 2.0) as an opportunity to share knowledge and experience, to exchange opinions and points of view.

RELATIONSHIPS. Some examples

SOCIAL NETWORKS AND NEW RELATIONAL RESOURCES IN HEALTH

- **Rate MDS** http://www.ratemds.com/social
  Online platform which allows users to search for doctors by specialism and rate health professionals so that others can use this information when deciding which doctor to approach. Available in the United States, Canada, United Kingdom, New Zealand and India.
- **Patient opinion** www.patientopinion.org.uk
  An initiative of the National Health Service in the United Kingdom which allows patients to evaluate the health system and share their experiences with other patients.

NETWORKS OF PATIENTS, FAMILIES AND CARERS

- **Inspire** http://www.clinicahealth.com
  Inspire builds online communities of patients, families and carers in a safe, protected environment. It is primarily funded by advertising and provides communities for nonprofit health organizations in the United States including Arthritis Foundation, Lung Cancer Alliance, National Organization of Rare Disorders, and the National Osteoporosis Foundation.
- **MedHelp** http://www.medhelp.org/
  MedHelp enables patients to contact medical experts and other individuals with experiences similar to their own. It claims to have 8 million users (September 2009) and is supported by institutions such as Cleveland Clinic and Mount Sinai.
- **Forum clínic** http://www.forumclinic.org
  This «interactive programme for patients», created by the Hospital Clínic with the support of BBVA, provides forums where patients can share their experiences and learn from other patients, in addition to finding emotional support. These spaces are moderated by a health professional. It currently has eleven forums on Chronic Obstructive Pulmonary Disease (COPD), schizophrenia, diabetes, ischaemic cardiopathy, breast cancer, depression, cardiovascular risk factors, bipolar disorder, arthrosis, arthritis and obesity.
- **Plataforma e-Catalunya** http://ecatalunya.gencat.net/
  The Government of Catalonia has made the e-Catalunya platform available to patients associations which want to create Web 2.0 spaces in order to have an internet presence and to communicate with their members.
- **Wepaciente**s http://www.webpacientes.org
  Joint initiative of the Fundació Biblioteca Josep Laporte and MSD designed to provide a point of reference for patients and a communication platform for patients' associations, who can use this website to promote their activities.

RELATIONSHIPS BETWEEN HEALTH PROFESSIONALS

- **iMedExchange** http://www.imedexchange.com
  A social network for doctors in the United States. Its aim is to promote the exchange of information between medical professionals, as a form of mutual enrichment through the exchange of knowledge.
- **Plataforma e-Catalunya** http://ecatalunya.gencat.net/
  The e-Catalunya platform, an initiative of the Government of Catalonia, is home to various virtual groups. These include the Health Portal, promoted by the Health Corporation of Barcelona, which is designed to provide a space for multidisciplinary collaboration and participation where health professionals and health managers can meet. The aim is to bring together proposals to improve the health services.
- **Medbook** http://www.medbook.es/
  Social network aimed at health professionals and created by PortalesMedicos.com. It allows users to create a profile, start discussions, share documents and create discussion forums. It is also open to students of the health sciences.

3. Telemedicine

46.2% of hospital and primary care centres in Catalonia have incorporated telemedicine, according to the most recent survey of ICT trends in the health service of Catalonia[8], a report drawn up annually by the Fundació TicSalut. The most widespread applications of telemedicine are:

- telediagnosis in radiology and dermatology
- teleconsultation involving patients with diabetes
- telemonitoring of chronic cardiac insufficiency patients

This study, conducted at 91 hospitals and primary care centres, found that one in every five doctors uses new technologies in their daily work, principally to communicate with their patients and to compare opinions with other leading health professionals provided by patients. However, despite the unquestionable benefits of applying new technologies, in 2007 only 1% of health expenditure was allocated to these tools, while in other European countries, such as Sweden, the level of investment was almost double this.

The demographic changes of recent years have led to increased pressure on care services: longer life expectancies, accompanied by increased dependency and chronic diseases, an increase in the immigrant population and limited numbers of specialists. In addition, people, especially the young, are more familiar with the use of new technologies. In this context, telemedicine facilitates access to diagnosis and treatment, helps make service provision more efficient, facilitates communication with specialists at leading hospitals without requiring travel, and enables patients with chronic conditions to be monitored.

Telemedicine also gives doctors better access to more specialist knowledge and reference sources, and allows them to compare information with other professionals, improving their capacity to resolve problems. New technologies make it possible to establish a more direct relationship with patients, and to monitor those with chronic illnesses without the need for either patient or doctor to travel to an appointment. Telemedicine can help reduce costs, improve the efficiency of service delivery and enable more rational use of existing resources, which are thus enjoyed by more citizens. It helps spread the demand for services more evenly and makes it possible for the health system to focus on the needs of its users. In addition, it improves responses to emergency situations (for example, sending vital parameters from an ambulance) and ensures that doctors and patients in remote rural regions do not feel isolated.

New technologies are also making it possible to speed up procedures, many of which can now be conducted over the internet. Most Primary Care Centres in Catalonia now allow patients to make an appointment over the web, and it is also possible to change one's family doctor or paediatrician electronically.

The Department of Health of the Regional Government of Catalonia has established a project to enable the sharing of medical records, bringing together all a patient's health information in a single place so that it can be consulted from any health centre. This has two purposes: to facilitate the work of health professionals and to improve health care and make it faster.

This initiative has been matched in other regions of Spain, and Andalucia, Extremadura, Castilla-La Mancha, the Valencia Region, the Basque Country, the Balearic Islands and Navarre have all introduced similar projects in their health centres. At the same time, the National Health System which is the responsibility of Spain's Department of Health and the Consumer is working on a digital medical records system which will make it possible to consult the records of patients in different regions. This system is expected to come into operation in 2010.

Compared to the many benefits which accompany the introduction of shared digital medical records, the ethical risks or challenges would appear to be relatively minor. One of the most frequently raised of these has to do with the information available to patients regarding who has consulted their data. Guarantees of confidentiality usually include a procedure by which the system checks that individuals have the relevant authorization before they are able to access a patient's medical records, and some associations have called for patients to be given the right to identify who has accessed their data[c]. Indeed, although the existing system would appear to be consistent with the legislation, some bodies have already advised the health authorities to regularly inform patients about who has consulted their medical records.

Although the implementation of digital medical records has been uneven across the different regions of Spain, there are online tools which enable patients to bring together and manage their own medical information. Internet giants such as Google and Microsoft have spotted a business opportunity in this area, and there are also a variety of private services available, some of which are identified below.

TELEMEDICINE. Some examples

- **CAT365** http://www.cat365.net/
  This channel allows citizens to manage all their interactions with the Administration in Catalonia, including those in the field of health.
- **CatSalut – Catalan Health Service**
  http://www10.gencat.net/catsalut/eng/index.htm
  The website of the Catalan Health Service allows users to consult personal data, apply for an individual health card, consult a list of health centres, identify out of hours pharmacy services, arrange doctors' appointments, etc.
- **Google Health** https://www.google.com/health
  Free, open service. Allows any US-based user of Google to create their own medical history, including X-rays, test results etc. The system can also link with hospitals to download data on complaints and treatments. In addition, users can search for medical specialists, consult them and even receive online diagnoses and prescriptions. Google assures users that only they have access to this information.
- **HealthVault** http://www.healthvault.com/
  This free, open service provided by Microsoft allows users to bring together all their medical information and to share it with whoever they want, using an invitations-based permissions system. In addition, the data can be downloaded onto mobile devices such as phones or PDAs, and alerts can be scheduled to advise users when they need to take medication, have a check-up or see the doctor. Microsoft also assures its users that this information is not shared with third parties without the user's consent.
- **Medical Opinion** http://www.m-opinion.com/
  Provides a second medical opinion over the web. It started by offering its services in Italy and eastern Europe, and has now expanded to operate worldwide.
- **Biotronik** http://www.biotronik.com/es/es/home
  This leading European biomedical company has created an internet-based home monitoring system which uses the GSM telephone network for patients with pacemakers and defibrillators. The company has conducted a pilot test using these devices at the Hospital de La Paz in Madrid.
- **Proyecto Chronic, Hospital Clínic, Barcelona**
  This is a programme for the global management of patients with chronic obstructive pulmonary disease (COPD) after discharge from hospital. Led by the Hospital Clínic in Barcelona, it permits telecare for chronic patients, monitoring of pathologies, and direct contact with a nurse via SMS, internet and phone.
- **Refrigerator chips**
  This is a sensor which is installed in the individual's fridge and emits an alarm signal if the fridge is not opened for 24 hours. The idea would be for it to be installed in the fridges of dependent elderly people living alone.
- **Electronic prescription**
  To date, the electronic prescription system has only been implemented in full in Andalucia and the Baleares, but the National Health System of the Ministry of Health and the Consumer plans to introduce it throughout Spain. In Catalonia, the introduction of electronic prescriptions began in 2006, in a number of health centres and pharmacies in the Terres de l'Ebre and Girona provinces, with the aim of gradually extending it to the rest of Catalonia.

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[c] In this regard, Miguel Ángel Mayer has argued that the risk of information leaks from medical records is slight, although he also noted that over the next few years we need to study whether the use of digital records has actually achieved the stated objective of improving patient care.

4. Business

There is a wide range of business opportunities on the net relating to the sale of medical services, products and technologies. Sometimes, the aim is not simply the direct sale of a drug but rather to predispose potential consumers and patients to ask their doctor for it. One recent study published in the journal Cancer[9] showed that patients with colorectal cancer who had searched the internet for information about their disease were more likely to receive the latest treatments than those who had not searched for information. In other words, not only was the patient's influence on the therapeutic option selected a real one, but this also frequently led doctors to prescribe the latest treatment when they would not have done so under other conditions.

In Spain, current legislation prohibits the sale of medication outside of pharmacies. In fact, the sale of medicines over the internet is forbidden almost everywhere in the European Union (although this is decided by individual member countries and is not the competency of the EU). Only the United Kingdom and the Netherlands allow access to certain non-prescription medicines over the internet. It is also important to distinguish between the sale of medicines through the websites of authorized online pharmacies and those made through websites of questionable legitimacy. When using authorized online pharmacies, tools such as electronic medical prescriptions make it possible to ensure that the medication has been prescribed by a doctor.

However, the purchase of medicines over the internet from untrustworthy sites is a very real and increasing problem, and it is estimated that three of every five medicines bought in this way are fakes. Why would consumers buy these sorts of products over the internet? The fact that a medical prescription is not required, the wish to acquire a medicine which is not sold in the consumer's own country, and the belief that buying over the web will be cheaper. The most common illegal internet-based transactions relate to the sale of anabolic steroids, slimming aids and drugs to enhance sexual performance.

In 2002, the Organization of Consumers and Users (OCU) conducted a field study to explore the potential risks related to the purchase of medicines over the internet[10]. For this purpose, the organizers of the study attempted to buy products from over 40 websites selling medicines from questionable sources. They succeeded in buying 16 products, the majority of which were delivered without their original packaging (enabling them to pass through customs controls without problems) and with no patient information leaflet. They also found that in order to complete the transaction all that was required was to give a name, a telephone, an address and a credit card number. Most virtual shops gave no information about the potential risks of consuming the product without any medical control. Furthermore, when the products sold were legal in Spain, it was found that the internet price could be as much as double the price in Spanish pharmacies. It is clear from this that the risks this practice present are no laughing matter.

The promotion of medicines over the internet is subject to the same laws which govern the advertisement and promotion of medicines throuh other media channels (Act 26/84 General legislation for the defence of consumers and users, Act 34/1998, General legislation on advertising; supplementing Royal Decree 1416/1994). The situation becomes more complicated when cross-border trade is concerned, as policies on the advertisement of medicines vary from country to country.

BUSINESS. Recommendations regarding the sale of medicines over the internet

WHO Resolution on the «Cross-border advertising, promotion and sale of medical products using the Internet»[11] urges all member states:

1) to review existing legislation, regulations, and guidelines to ensure that these are applicable and adequate to cover questions of advertising, promotion and sale of medical products using the Internet and to develop, evaluate and implement strategies for monitoring, surveillance and enforcement;
2) to collaborate in matters raised by use of the Internet, especially (a) the dissemination of information on difficult cases, (b) the cross-border advertising, promotion and sale of medical products using the internet, and (c) specific national measures for enforcement; to designate contact points for such collaboration; and to disseminate this information through WHO;

3) to promote the use of Internet to obtain scientific information about medical products, validated by competent health authorities to ensure the quality of this information.

And appeals to industry, health professional and consumer organizations and other interested parties:

1) to encourage their members, where appropriate, to promote the formulation and use of good information practices, where applicable consistent with the principles embodied in the WHO Criteria for Medicinal Drug Promotion;
2) to monitor and report problem cases and aspects of cross-border advertising, promotion, and sale of medical products using the Internet;
3) to maintain legal and ethical standards in the cross-border advertising, promotion and sale of medicinal products using the Internet.

These recommendations are based on Ethical Criteria for the Promotion of Medicinal Products as previously identified by the WHO.

5. Research

There have been two main drivers behind the revolution in biomedical research which is currently underway as a result of the expansion of the internet. Firstly, there are movements whose aim is to secure free access to information (open access movements, online peer review, pre-competitive public domain knowledge, etc.). And secondly there are the opportunities for conducting research on the internet, using vast databases shared by thousands of scientists throughout the world: in other words, globalized research.

On the principal that knowledge is universal and therefore does not belong to anybody, there have been various initiatives which have sought to ensure that the results of scientific research are shared. As this research is usually disseminated through the medium of scientific articles (published in journals operating a peer review system), the main concern has been to make these articles available to the public. This obviously represents a major change for the publishing industry, which has reacted in various ways. However, despite such misgivings, Open Access movements continue to make progress, with the support of major scientific organizations.

Open Access Initiative (OAI)[12,13] is an international movement led by researchers and academics whose aim is to promote free, unrestricted access to scientific and academic literature. The aim is both to democratize scientific knowledge and to increase the impact of research work by enabling it to reach a far wider audience. This is achieved in two ways: by publishing material in open access journals, and by directly entering articles in open access archives promoted by public and private institutions.

Open Access allows users to read, download, copy, distribute, print and link to the full text of scientific articles free of charge, as set out in the Budapest declaration, with the sole requirement being that the authors must be properly acknowledged. In other words, the information may be distributed so long as it is attributed to its authors and without commercial or profit-making motives. For this reason, the majority of open access initiatives are published under Creative Commons licences (http://creativecommons.org/international/us/).

Creative Commons (CC) is the name given to licences promoted by the American not-for-profit organization of the same name. They are based on the General Public License (GPL) of the Free Software Foundation, developed for computer software. The aim of CC is to provide a legal model which facilitates the free distribution and use of its content. In Spain, this movement is led by the University of Barcelona (UB).

RESEARCH. Examples of *open access* initiatives

- The Directory of Open Access Journals (DOAJ) http://www.doaj.org/
  This directory, established by the Open Society Institute of Budapest, is the most extensive index of open access journals. It lists almost 4000 journals, with free access to the complete texts.
- The Public Library of Science (PLoS) http://www.plos.org/about/index.html
  Created by a non-profit organization of scientists and doctors, its aim is to promote free access to scientific literature around the globe.
- Digital.CSIC http://digital.csic.es/
  Institutional repository of the Spanish Council for Scientific Research (CSIC) whose purpose is to organize and disseminate the results of the CSIC's research efforts, on an open access basis. Currently contains 9000 digital records.

The globalization of research takes a variety of forms: 1) immediate access to scientific articles, so that the latest advances become known more rapidly, 2) reducing the cost of accessing information, allowing funds which used to be spent on this to be redirected to other areas; 3) potential increase in the number of highly skilled people and the level of education they receive, thanks to the ease of accessing information and the availability of online training options; 4) promoting online working, by establishing links with researchers at other centres and in other countries, promoting the exchange of ideas and facilitating internet-based collaboration; 5) establishing cross-border multidisciplinary teams at low cost.

However, it also presents some challenges. The most important of these include: 1) the digital divide which separates rich countries from poor, as a result of which countries which lack widespread internet access or do not have broadband are at a disadvantage; 2) not belonging to an online scientific community discriminates against those researchers who find themselves excluded due to limited resources, poor computer literacy or a simple lack of interest.

A direct relationship has even been observed[14] between the scientific activity of researchers (measured by number of articles published) and the amount of information they receive from the internet.

RESEARCH. Pre-competitive knowledge commons

(Quoted from «Wikinomics», by Don Tapscott and Anthony D. Williams[15])

«The Human Genome Project represents a watershed moment, when a number of pharmaceutical firms abandoned their proprietary human genome projects to back open collaborations. […] So what exactly were these firms up to? We call it a 'precompetitive knowledge commons' […] a new collaborative approach to research and development where like-minded companies (and sometimes competitors) create common pools of industry knowledge and processes upon which new innovations and industries build.».

6. Cooperation

One year ago, the online version of Spanish daily newspaper *El País* asked its readers the following question: do you believe that social networks can promote solidarity?[16] Of the 348 people who responded, 78% replied that they believed these tools constituted a new pathway for channeling such initiatives.

At around the same time, the New York-based NGO Takes all Types launched an application to recruit blood donors from among Facebook users. The NGO then sends out a message to members of the group when their blood type is needed in the region where they live. It also sends out regular reminders to give blood. Another solidarity initiative is «Causes», a program created by Project Agape and designed to raise funds for humanitarian causes. Both initiatives constitute part of what is known as Web 2.0 activism or digital activism. Alongside this, the Cooperation 2.0 movement has also sprung up.

Recently the 2nd International Meeting on ICT for Development Cooperation was held in Gijón in Spain (http://encuentro2009.fundacionctic.org/), organized by the Fundación CTIC (Technological Centre for Information and Communication). The event took place from 10 to 12 February, under the title «Innovation in ICT for Human Development», with the aim of facilitating access to new technologies in developing countries. The participants identified the new opportunities for collaboration and dialogue offered by social networks, which can play a key role in redefining cooperation networks. At the same time they stressed the importance of acting locally, despite the fact that we live in an increasingly global world.

The usefulness of blogs, wikis and collaborative tools in general in responding to crises has been demonstrated on several occasions. One of the earliest examples was the response to the Indian Ocean tsunami of 26 December 2004, when an undersea earthquake was followed by a tsunami in south-east Asia. The metablog «Tsunami help» (http://tsunamihelp.blogspot.com/) was created to provide real-time information about what was happening in the various countries affected, and to organize aid. The blog also helped locate people who had disappeared, by publishing photos of them on the internet.

The new technologies offer new possibilities for citizens' participation, collaboration and social cooperation. The web allows people to join forces and helps bring volunteers and NGOs together.

COOPERATION. Some examples

- **Haces falta** http://www.hacesfalta.org/
  This project, led by the Fundación Chandra, uses ICT to promote participation and interaction between different members of society in order to implement social cooperation projects. The web portal brings NGOs together with businesses, public bodies and individuals who are able to help them meet their requirements. It has a noticeboard and a search facility for volunteers.
- **Online Volunteering** http://www.onlinevolunteering.org/
  Similar initiative, but on a global scale. This is the United Nations Online Volunteering service, «one of the tools used by the United Nations Volunteers programme (UNV) to mobilize volunteers for development,» according to the website. During 2007, it handled 3,800 applications for online cooperation, and over 80% of participants (both organizations and volunteers) rated their experience as either «good» or «excellent». Health is one of the development fields in which cooperation is offered, and the website has a search engine which makes it easier to search for resources and opportunities.
- **Voluntarios UAH** http://www.voluntariado.org/uah/
  This is the Portal for Cooperation and Volunteers of the University of Alcalá, Spain's first university portal to promote and manage volunteer activity on the internet, launched in February 2009. It is supported by the Fundación Chandra.

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The Virtual Nurse

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The Virtual Nurse is an e-health nursing project which treats the person as an inseparable whole which cannot be broken down into its constituent parts, and takes a multi-dimensional approach to health which sees it as a means of improving people's lives rather than as an end in itself. In this regard, the virtual nurse is designed to fill what we see as a vacuum in the e-health sphere, a vacuum which raises one of the principal challenges and duties of e-health: the need to ensure that our definition of e-health is consistent with an integrated rather than a partial concept of health.

The concept of health is one which has changed throughout history. In 1948 the World Health Organization (WHO) offered the following definition[a], «A state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity.» This definition is one which now sounds outdated and, in my opinion, questionable, both for the use of the word *state*, which depicts health as something static when it is instead something which is constantly changing, and for the word *complete*, which among other things makes this definition of health almost impossible to ever attain. An alternative definition, drawn up in Perpignan in 1976[b], refers to «a way of living based on solidarity, independence and joyfulness», and makes reference to well-being, to feeling well, as a part of living and not just as an objective to be achieved.

The reality, however, is that we continue to talk of health when illness appears, and this leads to a worrying simplification of the concept. And so, just as happens in traditional face-to-face settings, e-health too is based on a paternalistic, biomedical model. All you have to do is perform a random search for key words, identifiers or the most common words in discussions of e-health, ICTs and health both in Catalonia and elsewhere (articles, websites, the media). These are words like *illness, risk factors, patient, doctor, telemedicine or telecare, medical history* etc. Although in most e-health publications[c] we also encounter words such as *health, healthcare* or *quality of life,* these are frequently used to refer to illnesses, treatments or tests, etc.

The focus on the biophysiological dimension of health, the reduction of this dimension so that everything is seen simply as a pathology which has to be cured, the focus on illness rather than health promotion (both in prevention and care), a unidirectional care model in which the health professional gives and the service user receives, all lead to a simplification of what healthcare is which heavily influences the nature of the care and attention which people are offered, whether face-to-face or on a virtual basis.

In contrast, we believe the concept of health should not be bound to that of illness, that health is something which does not only affect those we classify as patients but is, instead, a «way of living» which is the real concern of the work of all health professions. In light of this, we identified a key duty and a key ethical challenge of e-health:

- To consider the potential of the e-health space in the context of an integrated concept of health.
- To use the potential of e-health to make good the shortcomings of face-to-face care by promoting people's health and creating a sustainable model of health in which all the actors[d] assume their own responsibilities, as far as is reasonable.

The Virtual Nurse portal represents an attempt to address these concerns.

The first question we asked ourselves when we considered creating the Virtual Nurse portal was how to create a health portal where people could

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[a] World Health Organization. Health Promotion Glossary [on line]. [Consulted: 2 April 2009]. Available at: http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf.

[b] Congress of Catalan-speaking doctors and biologists, 1976, Perpignan.

[c] Contextualized examples. Article selected randomly: *Siemens in integration agreement with Hospital Clínic, Barcelona (2008) Healthcare IT News*. From this article we can see how the concept of health care is constantly used with reference to treatment and tests. Moreover, and as an example, it states: «*In the case of early detection of a prenatal condition, we hope to ensure the health* (referring here to the control of illnesses or health problems) *of unborn babies* (ensuring the health of a baby is far more complex and involves much more than the presence of a prenatal illness)». Bibliographical reference: *Siemens in integration agreement with Hospital Clínic, Barcelona (2008) Healthcare IT News.* [19 January 2009]. Available at: http://www.healthcareitnews.com/news/siemens-integration-agreement-hospital-clinic-barcelona-0.

[d] Actors: Administration, health professionals and users.

find information, advice and suggestions which would enable them to take steps to live healthily and feel well, irrespective of whether or not they suffered from a health problem. A portal where everyone could find information about health without the need to refer to illness. We referred to a specific conceptual model of nursing[e] (nurses are concerned with people's health, which is not the same as being concerned with patients' illnesses) when organizing the information, to highlight three key thematic blocks on the website. The first of these was entitled «Activities of daily living», the second was «Life situations» and the third was «Health problems».

The Virtual Nurse uses these three blocks to provide health information on the internet which has been adapted to the needs and situation of all, whether «healthy or not», with the aim of supporting them and improving their capacity for reaching decisions about their health. In other words, the Virtual Nurse is a health promotion[f] medium. It is intended to accompany people before, during and after the prevention of and/or care for health problems, and promotes the active participation, responsibility and autonomy of individuals in their health care, providing them with the power to take decisions, with the support, if necessary, of a health professional.

An example of this is provided by the way the Virtual Nurse addresses the issue of smoking[g]. This file has three sections: nurse's advice, general information, and related information. The advice section provides advice from the nurse about how to carry out activities of daily living, to look after one's health, and to improve one's quality of life, including advice on how to give up smoking. The general information section provides a definition and history of tobacco addiction, discusses related factors such as sociocultural, economic and political factors, provides information about how tobacco is consumed, and offers a typology of smokers. The related information section covers the structure and function of the human body; the relationship between tobacco consumption, situations of daily living and health problems; giving up smoking; factors and behaviours to protect against the dangers of tobacco use; and risk factors. The approach is based on providing information about this risk situation so that website users are better able to look after their health, whether they are smokers or not, and whether they wish to give up or not. The combination of the information and face-to-face support give the user the power to decide rather than taking the decision on his or her behalf, or reducing the content on tobacco use to a mere explanation of how to give up or of the consequences of failing to do so.

How should we use ICTs in e-health to help people look after their health?

The Virtual Nurse has been built using health education[h] as its methodological working model, informing the functional analysis, design and technological development of the website, and conditioning each of the decisions taken. The Virtual Nurse is a website which, in addition to offering information, seeks to educate people and to facilitate the task of change. In other words, it is concerned with "caring" in every sense of the word, taking into account each person's unique perceptions and feelings, and reflecting the individual nature of different internet users.

It does this by means of an integrated health knowledge site, at a single URL, which has been created and developed on the basis of the user's perspective and his requirement to care for her health and not simply to provide information about specific issues. For example, when discussing diabetes or pregnancy, the aim is not simply to write about the topic but to consider what a person with diabetes or a pregnant woman needs to know in order to care for

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[e] Orem, D. *Modelo de Orem*. Barcelona. Masson-Salvat Enfermería, 1993.

[f] Health promotion is the process of enabling people to increase control over, and to improve their health. World Health Organization. Health Promotion Glossary [on line]. [Consulted: 22 November 2008]. Available at: http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf.

[g] What You Need to Know File: Tobacco Use http://www.infermeravirtual.com/es-es/problemas-de-salud/situaciones-de-riesgo/tabaquismo/consejos-de-la-enfermera.html

[h] Health education comprises consciously constructed opportunities for learning involving some form of communication designed to improve health literacy, including improving knowledge, and developing life skills which are conducive to individual and community health... [On line]. [Consulted: 2 April 2009]. Available at: http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf

their health, and these needs often go beyond what users themselves perceive and which thus generate the original demand for information. This means that users can find not only the information they are looking for, but also other information which nurses, as health professionals, believe users may need in order to look after their health, and which may go beyond what is required simply to control illness when this is the reason for the search.

Let us continue with some real examples taken from the website. Let us take the example of a woman who has suffered a miscarriage whose nurse or midwife, in addition to providing face-to-face support and using the Virtual Nurse as a tool in her work caring for the health of others, suggests to the woman that she consult the Virtual Nurse with regard to any concerns she may have about her «health situation». Under the heading «Health problems related to pregnancy»[i], in addition to the usual information about normal signs and symptoms and warning signals, there is also a link to the section of the website which deals with a situation of loss or grieving. The user decides whether to click or not, whether to do it now or later, and whether to discuss it at her next appointment with her nurse, midwife or gynaecologist.

At the Virtual Nurse we take a positive view of the fact that looking for information about health is one of the main reasons of internet searches, as this means that we do not have to create demand. The web provides the possibility of giving users the integrated information they need to control or improve their health or quality of life, and this information is provided in the form of links, strategically placed by a nurse, to give each person the power to decide whether to click or not.

This interactivity, and the links between content is what makes it possible to offer users the information they are looking for, together with the information which we as health professionals and nurses think they may need to look after their health. It also allows us to develop any web content in a distinctive, collaborative manner.

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[i] What you Need to Know File: Pregnancy: http://www.infermeravirtual.com/es-es/situaciones-de-vida/embarazo/consejos-de-la-enfermera.html.

The website is organized around the three major thematic blocks of the Virtual Nurse website –Activities of daily living[j], Life situations[k] and Health problems[l]– which constitute a major source of information offered to users in an interactive, interlinked way to transform it into nursing knowledge which is directly available to people.

Each thematic block consists of different themes: the eight activities of daily living[m], the situations of life (adolescence, adulthood, grieving, pregnancy, infancy, menopause, old age, travel); and health problems (diabetes, schizophrenia, fibromyalgia etc.), all explored as part of a graphic unit with the title What You Need to Know File (FQNS), which organizes and brings together the content and is used as a framework for organizing them. In addition, it

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[j] Activities of daily living are those requirements which individuals must satisfy within a specific timeframe in order to sustain life, function healthily, ensure their continuous personal development and to deliver the highest possible level of well-being and quality of life. Activities of daily living include breathing, eating and drinking, moving, resting and sleeping, eliminating and preventing risks, communicating and interacting socially, and working and enjoying oneself. Definition by Carmen Fernández Ferrin and Maria Teresa Luís Rodrigo for Virtual Nurse. Available at: http://www.infermeravirtual.com/es-es/recursos/glosario/lista-de-terminos.html?CurrentFilterWord=A [Consulted: April 2009].

[k] Situations of life are those situations related to a change in one's health, in the developmental stages, or in the conditions of life, which require a person to change his daily habits and his idea of himself in the social context in which he finds himself. Definition by Carmen Fernández Ferrin and Maria Teresa Luis Rodrigo for Virtual Nurse. Available at: http://www.infermeravirtual.com/es-es/recursos/glosario/lista-de-terminos.html?CurrentFilterWord=S [Consulted: April 2009].

[l] A health problem is a problem related to a health-related state or process experienced by an individual, a family or a community. People's health problems do not only affect specific bodily structures and the physiological or psychological mechanisms invlved, but may also have a varying degree of impact on the person's overall function. Definition by Carmen Fernández Ferrin and Maria Teresa Luis Rodrigo for Virtual Nurse. Available at http://www.infermeravirtual.com/es-es/recursos/glosario/lista-de-terminos.html?CurrentFilterWord=P [Consulted: April 2009].

[m] Domingo Pozo, M. and Gómez Robles, J. «El concepto de Necesidad Humana Básica como aproximación a la definición del cuidado». Índice de Enfermería [Index Enferm] (digital edition) 2003; 43. Available at: http://www.index-f.com/index-enfermeria/43revista/43_articulo_23-27.php. Consulted on 1 April 2009.

enables interaction between the different areas of content, promotes the sharing of knowledge and makes it possible to avoid repetition.

A What You Need to Know File is never an isolated piece of content, but instead forms part of a unit of information which corresponds to a situation or experience in the life process of an individual. For example, pregnancy[n] is a life situation which, in addition to being a FQNS, forms one of the information units of the Virtual Nurse, which interlinks the different contents and FQNS: Breastfeeding, Childbirth, Eating and pregnancy, Physical activity, the eight activities of daily living, Adulthood, Adolescence, Nausea and Vomiting, Pain, Medicines and The Female and Male Reproductive System, from the block Structure and Function of the Human Body. The aim is to create a single website which provides an integrated response to the different health needs of the user.

All of the content on the Virtual Nurse goes through a complex creation process[o] and an online review circuit until the content or individual FQNS has been created. The FQNS consists of a central body, which is the public content, plus complementary resources (the glossary, the bibliography, the links, the authors etc.) and other elements, such as health tutorials[p] designed to meet the needs of each user.

The Virtual Nurse, then, is a Web 2.0 tool, a wiki where nurses create, edit and share knowledge and make it available to others, thus creating disciplinary consensus.

The Virtual Nurse is:

- A knowledge space about health and nursing. A working tool for nurses and other health professionals, both as part of their professional development and to improve the health care offered to users, offering continuity in nursing care and in the care process. An educational resource in the teaching environment.

It is an e-health tool which goes beyond the patient-doctor relationship, preventing and caring for illness in hospitals or specialized centres. It is also a tool for people (users) and for health professionals, for health promotion and for integrated, community care.

It is a tool which offers people a new route to health care, where the face-to-face and virtual spaces come together and complement each other, offering people a care model which will gradually adapt to the new requirements of the 21st century.

This project finds expression in the Virtual Nurse: www.infermeravirtual.com.

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n. What You Need to Know File: Pregnancy: http://www.infermeravirtual.com/es-es/situaciones-de-vida/embarazo/consejos-de-la-enfermera.html

o. The process of creating content consists of a working cycle which is repeated as often as necessary until the relevant FQNS or content has been created: selection and training of author, structural and pedagogical review, disciplinary review, adaptation and integration of web content, development of added value elements for each file (bibliography, glossary, relevant links, etc.), correction and translation (Catalan/Spanish), entering it in the Content Management System, and publication. The plan is to perform a twice-yearly revision of content by theme and author.

p. Tutorials: recommended navigation routes, adapted to the different situation each individual may be living through. For example, the What You Need to Know File for diabetes suggests three recommended routes depending on whether the person looking for information has been diagnosed recently or not, or if they are looking for specific information for children and young people. http://www.infermeravirtual.com/es-es/problemas-de-salud/enfermedades-transtornos/diabetes/consejos-de-la-enfermera.html.

Contributions from working groups

Relationships

Francisco Lupiáñez-Villanueva, ***Lecturer in Information and Communication Sciences. Open University of Catalonia***[a] ***(spokesperson)***

Leticia Costas, Sara Sentís, Marie Czamanski and Helena García, ***students on Master's Degree in Scientific, Medical and Environmental Communication at Pompeu Fabra University of Barcelona.***

Internet as interaction, relationship and use

The internet described in the working paper, an internet of information, of control and of quality, is not the internet of young users. They are not patient, even if they will be in the future, but they are already citizens. In our opinion, the internet is both a technological and a social change. The people in our working group have grown up with the internet and as a result they see it as a way of interacting, of relating to each other, something to use and not as a source of information, of quality, of telemedicine.

The internet represents interaction in on-line and off-line relationships. The doubts raised regarding digital identity, where it is impossible to separate one's personal from one's professional identity, do not concern young people. There is no difference between the off-line identity and the digital one because the two are integrated.

The Internet, for young people, is a space in their lives, one which enables them to relate to people, organizations, issues and interests. Their relationships over the internet are not one-way, they do not simply search for sources of wisdom, but instead interact.

They comment on content with each other over the internet and have no concept of information as such. Young people believe they have sufficient judgement and independence to decide about the information they receive over the Internet. They can ask about this information and assess it with their network of contacts or other people, either on the internet or elsewhere.

In our opinion, health professionals need to change their role in order to promote interaction with the internet. In the private health sector they are already doing this. In fact, one of the observations of the study of technological modernization was that the people who use the internet to access the health services are predominantly the well educated and the well off. When people use the internet to interact with the health system it is with the private health sector.

There is therefore a need to open channels of communication. Key to this are interactive spaces which make it possible for information to be shared and expanded. The control over information which the medical profession had years ago is no longer as strong as it was. If you want to guide internet users then it has to be on the basis of a relationship of trust. This has to be a relationship between equals, and doctors therefore have to undergo the same transformation as that which has been experienced by other professions.

Our group was unconvinced by seals of quality on websites. We doubt whether users notice them, and there will be disagreements when it comes to assessing the quality of information and the criteria used.

Challenges

Relationship with organizations and professionals

The challenge identified by our group was, «What can the internet do for my health?» Internet users would to be able to discuss the full range of health-related issues with health professionals. Just now they are connected, but only to their own research networks or on networks created to enable them to collaborate with each other, not yet with the patients. Hospitals and primary care centres tend to be rigid, hierarchical structures which hinder internet-based relationships.

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[a] Principal investigator for the study «Technological modernization, organizational change and service to users in the health system of Catalonia». Proyecto Internet Catalunya (PIC). UOC and Generalitat de Catalunya. http://ictconsequences.net/uoc/internetsaludsociedad/

Young people's concerns go beyond the internet. There is also a lack of interaction elsewhere, with information that users find on the web and wish to discuss with their doctors. As was mentioned, there is a certain fear of losing control over information. Furthermore, doctors have little time for each consultation and, even if they want to, are unable to go online to talk to their patients. As a result, there are structural issues which prevent the consolidation of the internet in organizations.

Another issue to note is the need to interact not only with the expert knowledge of health professionals, but also with the lay knowledge which arises from the personal experiences of ordinary internet users. Forums or spaces for interaction about health are no longer restricted to health institutions but have spread beyond these spheres, and both are the source of useful knowledge.

Transition from an industrial society to a networked society

The second challenge is raised by the necessary transition from an industrial society to a networked society. Those who most need the internet are the over-55s, as they are the principal users of the health system. The challenge is how we help this group join the networked society.

At the same time, the young people of today are the patients of tomorrow, and they therefore consider how they can help the new technologies become established in the health services. Not just over the net, but also when they see a doctor, and they want to have five minutes to say that they have found something on the internet and to be able to check the information.

Finally, in the future we will increasingly be talking of social divides on the basis of classic variables such as education, age or income, and not of a digital divide, because access to a computer with internet access will be less of a barrier. It is true that there is a part of society which is not on the internet, but that is because they don't want to.

Information

Beatriz Viejo, ***Scientific Editor specializing in health (spokesperson).***

Miguel Ángel Mayer, ***Director of Médica Acreditada website, Official College of Doctors, Barcelona.***

Gisel Fontanet, ***Nurse seconded to Programme Management, Official College of Nursing, Barcelona.***

Johanna Cáceres, ***Director of Communication at the Catalan Oncology Institute.***

Ana Lozano and Cecilia Valenza, ***students on Master's Degree in Scientific, Medical and Environmental Communication at Pompeu Fabra University of Barcelona.***

The importance of health information

Information is a health intervention, one which is sometimes compared to other treatments or to surgery. The information which patients are given has a major influence on health outcomes. However, as was noted in the session, health is more than this, it is not just illness but also personal well-being. Although it's obvious, when you provide information about health you have to know who is receiving the information and why.

E-health as an instrument and guide

E-health is not a separate entity, but an instrument which must coexist with reality, which makes it possible to promote health education: promoting health, preventing and caring for illness.

Our group sees e-health as an instrument, a guide which accompanies or supports health education, providing tools which enable the user to take decisions, strengthening the capacity for shared decision-making, discussing with other health professionals, and taking joint decisions. All of this complements face-to-face care which is not restricted to caring for illness.

Guiding does not mean controlling but rather, in this case, refers to moderating, to orienting the user. There is so much information available on the net, and patients need help in evaluating it.

E-health cannot exist on its own, just as traditional personal care now relies on e-health for information, support and assistance.

E-health resources need to be institutionalized, ensuring that everyone becomes involved with them. They should not be left in the hands of doctors or health professionals, but instead everyone affected should take part. This is not happening yet. There is a perception that e-health does not require additional resources, but instead reduces the amount of resources consumed by the health sector. This is an issue which remains to be addressed.

User guidance

Although our group sees e-health as a tool which guides decision-making, we should remember that sometimes the user feels alone and needs guidance when searching for information. This is why there is a need for user guides and website accreditation. So far, there has only been accreditation of medical websites, but there is a need to go further and also accredit health websites.

At the same time, this accreditation should be more visible. For example, it could be indicated by web browsers. We are in favour of Web 2.0 tools, such as wikis or forums, but we would like these tools to be accompanied by more guidance.

Cooperation

Maria Dolors Navarro, ***Assistant Director of the Fundació Biblioteca Josep Laporte (spokesperson).***

Noemí Duran, ***Planning and Systems Service at the Catalan Institute for Oncology.***

Roser Bosser and Neus Pavón, ***students on Master's Degree in Scientific, Medical and Environmental Communication at Pompeu Fabra University of Barcelona.***

Definition

We have decided to start by defining cooperation. For our group, it refers to collaboration between different individuals or groups, with the aim of achieving a common goal. There are three types of cooperation:

- Material: for example, Wikipedia, where different people cooperate to share knowledge or content.
- Physical or economic: as in the case of collaboration between different groups. One of these groups was buying new furniture and it made the old furniture available to those who wanted it. This initiative was coordinated over the internet.
- Action-based cooperation: this covers different initiatives, such as exchanging domestic or care tasks.

Classification

Broadly speaking, cooperation can also be classified according to its origin (generated by users or by institutions) or by its scope (international or local).

Some cooperation arises from emergency situations. This is the case with environmental disasters or health emergencies which give rise to movements to provide aid. Cooperation can also be the result of planned initiatives involving a range of institutions, as is the case with patients' associations.

There are also examples both of international cooperation, as we often see with NGOs, and local initiatives, while disparities in technology create a need for local cooperation.

Challenges

We identified two major challenges for cooperation. Firstly, we are experiencing major changes at a technological level, where there is a two-speed process. While the pace of the changes occurring on the internet is extremely rapid, society responds to these far more slowly. As a result, we need to consider what society needs if it is to be able to adapt to these changes. We believe it is necessary to provide training and guidance if people are to be able to distinguish between the quality, the reliability of the sources, and the safety of information.

Even if individual needs are met, we also need to consider the issue of social justice. In addition to the needs of individuals, we also require altruism and cooperation to improve the current situation.

Research

Xavier Carné, ***Head of the Clinical Pharmacology Service at the Hospital Clínic, Barcelona (spokesperson).***

Gonzalo Casino, ***Journalist with the Health Section of El País newspaper (spokesperson).***

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The ownership of research

Until a few years ago, research was considered to be the property of the sponsor who had financed. Now, after many years of campaigning, there is a consensus that clinical research results are the outcome of an interaction between many individuals, including the patients, and this gives rise to the right that this information should be public, free and accessible to all.

This has led to the creation of databases of clinical drug trials, thanks to the efforts of the publishers of medical journals, research groups and campaign groups. In some instances, for example, pharmaceutical companies had concealed information about the effects of drugs on adolescents with the result that people were unaware that certain treatments carried a risk of suicide. Pharmaceutical companies have responded, some better than others, with the result that there are now accessible databases. The most widely used is www.clinicaltrials.gov, compiled by the United States government, which contains both the study results and the procedures used. The WHO has also created a portal of portals, which is designed to function as a start point for accredited information. On Google it is possible to pay for a site to be listed in the top positions, and this creates an economic bias.

Research method

Historically, the method and ethics of clinical research have developed out of clinical drug trials. Although research affects many other changes, these have followed in the wake of drug research, something which we believe is likely to continue.

The state as sponsor

The state is beginning to fund non-commercial clinical research, but it does not fund the dissemination of the resultant knowledge. For researchers, this has created a strange system. Although professional academic careers are in theory based on three factors – research, care and teaching – in practice research is privileged, to the detriment of the other two areas.

Access for poor countries

Research is becoming more accessible to poor countries. For a long time it was dominated by the English-speaking world, but this is now changing rapidly thanks to the internet and the way in which it facilitates communication.

Interaction between researchers, patients and service users

Research has little meaning if it is not accessible to users. Patients' and other associations are playing an increasingly important role. Often, there are associations which are funded by commercial interests, and this obviously raises the issue of conflicts of interest.

Opaque research

Although there is the impression that more and more research is available on the internet, much of this is opaque for all but the specialist reader. For example, *PubMed* (which is now freely available) is of very little use to the general user because it offers technical information aimed at specialists. Another example is the genome project. Although this is all over the internet, who can actually read it or understand it?

Dissemination

Thanks to the internet, many researchers are taking on the role of disseminators. They have their websites and their blogs, where they publish everything they do. This increases the presence of research and science in society, but it should also be noted that this effort is often self-interested in that it is designed to help obtain research funds. One should not confuse this kind of dissemination with journalism, which is neither communication nor dissemination but rather putting what researchers say in context and putting oneself in the shoes of the ordinary person, whose interests are being defended.

Another issue raised by Gema Revuelta was that of free access to research. The publishing group PLOS (Public Library of Science) has completely changed the business model for how scientific results are sold, which has traditionally been in the hands of large publishing companies such as Elsevier, publisher of *The Lancet*, whose business is built around the sale of journals. PLOS has changed this model and offers free access to everyone, not just to researchers. The editorial cost is met by authors or researchers, and thus has to be included in the research costs. This is changing the business model, and publishers are obviously seeking to resist this. However, the prevailing trend is for public research to become increasingly accessible via the internet. The filters have not changed, and there continues to be peer revision and the same publication requirements as before, with research which fails to meet these being rejected, and in fact a fairly high percentage of the papers submitted do not make publication.

Another phenomenon noted was the way in which the internet offers publishers a way of reaching a wider audience. The journals themselves act as communicators, disseminating and contextualizing the research. One example is the *British Medical Journal*, which has created its own channel on You Tube, while another approach being tried out is to require researchers to submit a summary which is comprehensible for a non-specialist reader, along with the original research paper.

Many researchers are finally accepting their social responsibility to act as communicators. Before, many researchers conducted their work without telling others about it. Now, the majority are realizing that part of their work is to tell people about what they are doing. We should not forget that much research work is performed using public funds, and that the general public are therefore also the patrons. All of this raises another set of issues, those relating to intellectual property.

Another example to be considered is that of the Cochrane Library (http://www.cochrane.es/) which brings together the best articles and reviews in the health sector, and is accessible to all, both in Spain and other countries. In Spain, the Centro Cochrane Iberoamericano is funded by the Spanish government, and enables users to search on any health-related topic and to find answers, often of a fairly accessible nature. The website is fully accredited. Another website which has been established recently is Excelencia Clínica (http://www.excelenciaclinica.net). The problem is that many people are unaware of these resources, even though they provide excellent access points to research on the internet.

Other ideas we noted included the notion that science is counter-intuitive. A book well worth reading in this regard is Lewis Wolpert's *The unnatural nature of science*. This explores the divide between how researchers and non-researchers see science. While non-researchers demand certainty and clear messages, researchers know that this is difficult. The world of health is one of uncertainty and as a result communicating its science is complicated, as is scientific journalism.

Telemedicine

Francisco Beldarrain, *Doctor and Advisor to NET2U (spokesperson).*

Victoria Camps, *Professor of Moral Philosophy at the Autonomous University of Barcelona and President of the Víctor Grífols i Lucas Foundation.*

Marta Ciércoles, *Journalist with Avui.*

Carmen Fernández, *Senior Editor in Catalonia for Diario Médico.*

Joan Guanyabens, *Chief Executive of the Agency for the Evaluation of Medical Technology and Research with the Regional Government of Catalonia.*

Sonia Liñán and Mar Santamaría, *students on Master's Degree in Scientific, Medical and Environmental Communication at Pompeu Fabra University of Barcelona.*

Confidentiality

We have concentrated exclusively on the ethical challenges of e-health. One very important aspect of telemedicine is the issue of electronic medical records, and this gives rise to a series of ethical concerns. With regard to electronic medical records, we discussed various issues which concerned us, one of which was the question of confidentiality. If my medical records can be accessed electronically, how can I be sure they are confidential? We also drew many comparisons between the real world and the virtual one, because medical records stored in a filing cabinet are not necessarily particularly confidential. However, the fact remains that technology can be misused to access far more information, while people are less likely to gain access to a filing cabinet for the same purpose.

Taking responsibility

The second issue we discussed was that of individual responsibility for one's medical records. According to the law, medical records have always been the property of the patient but until now, until they became available electronically, this fact had little real meaning. Now, this information is not held by a doctor or a hospital, and they therefore lose some of the access to this information while I am the one who determines who can have access to it. We discussed the issue of how I can be sure of receiving the information and how I can control who accesses it. These are rights which we have by law but which we have not yet begun to use. It is something almost nobody is aware of.

We are currently experiencing a paradigm shift with regard to this information. Before, it was the property of the doctor, and he did what he liked, whereas now it belongs to the patient. As a result, everyone has to change: the doctor, the system and the health service user.

Dehumanization

Another issue we discussed, particularly with regard to telemedicine and telecare, was the dehumanization of human interactions when we use technology to communicate. We only discussed this issue very briefly, because our experience was that social networks are actually generating a vast range of contacts between individuals which did not exist before. Victoria Camps cited as an example the case of a lecturer with the Open University of Catalonia who had both face-to-face and virtual students. This lecturer explained that his contact with virtual students was actually much closer than with face-to-face students. They discussed more issues, communicated more, chatted, sent each other emails, etc. By contrast, the face-to-face students attended classes, listened and left. In other words, it is far from clear that technology leads to a dehumanization of relationships. In the case of health, providing home-based patients with technological tools provides a degree of reassurance. They know that if something happens to them they can raise the alarm.

Security

We also considered the question of how we ensure the security of e-health. This greatly complicates the implementation or extension of medical records. Although the law makes it very clear what levels of security there must be, this still has to be applied in reality.

Benefits and challenges

All of these issues arise within a context which also brings many benefits, with the introduction of unified medical records offering equity, accessibility, speed and quality. People in remote locations can receive a quality of care similar to that which is available in cities. The challenge is how to identify and address the risks indicated here.

There are two further issues which are not necessarily specifically related to telemedicine or electronic medical records, but rather to information in general. The first of these is the danger of websites offering counterfeit drugs, and treatment recommendations which do not comply with health regulations. This needs to be addressed.

The second issue is that of disinformation and information overload. The sheer quantity of information available on the internet means that we are in danger of creating urban myths, of believing false information, or of having so much information that we become incapable of distinguishing what is relevant from what is irrelevant.

Proposals

Now that we have identified these issues related to e-health, we have suggested a number of points which we feel need to be addressed in order to prevent or mitigate potentially negative effects:

- Promote education and training in the use of information. Teach people to distinguish between sources which are reliable and those which are less so, between information and opinion.
- Make people aware of their rights. I have the right to control my medical records, and I can have ask who has accessed it. This is something almost nobody is aware of, and it is important that people know about these rights and are able to exercise them.
- Inform about the risks which derive from things not being done properly or from releasing certain clinical information.
- Dissemination of accreditation. We believe in the online accreditation discussed by the other groups. The fact that so much information is now available means we must help people to identify information which is based on scientific knowledge. Although people are entitled to hold a range of opinions, not all of these constitute good medical practice. The problem of accreditation is that people don't know what to look for. There are lots of accreditation schemes. Accreditation should be more widely known, and people should know where to look for it. It is not so much an issue of knowing whether a particular site is accredited or not, but rather of knowing if people see accreditation as importation.
- Promote the digital identity of doctor and patient. This should be used systematically, so that whenever a doctor writes on a website it would be indicated. It should be certified, showing that what has been written is the work of a doctor and therefore has a certain value.

List of participants in the seminar

Speakers

- Gema Revuelta.
  Assistant Director of the Scientific Communication Research Centre of the Pompeu Fabra University.
- Gisel Fontanet.
  Nurse seconded to Programme Management, Official College of Nursing, Barcelona.

Coordinator

- Vladimir de Semir.
  Director of the Scientific Communication Research Centre of the Pompeu Fabra University and member of the Board of Trustees of the Víctor Grífols i Lucas Foundation.

Invited specialists

- Francisco Beldarrain.
  Doctor and Advisor to NET2U.
- Montserrat Busquets.
  Professor at the Department of Nursing and Basic Medicine, Lecturer in the Department of Nursing and Basic and Surgical Medicine at the School of Nursing at the University of Barcelona.
- Johanna Cáceres.
  Director of Communication and Knowledge Management at the Catalan Oncology Institute.
- Victoria Camps.
  President of the Víctor Grífols i Lucas Foundation.
- Xavier Carné.
  Head of the Clinical Pharmacology Service at the Hospital Clínic, Barcelona.
- Gonzalo Casino.
  Journalist with the Health Section of *El País* newspaper.
- Marta Ciércoles.
  Journalist with *Avui*.
- Noemí Duran.
  Planning and Systems Service at the Catalan Institute for Oncology.
- Carmen Fernández.
  Senior Editor in Catalonia for *Diario Médico*.
- Joan Guanyabens.
  Chief Executive of the Agency for the Evaluation of Medical Technology and Research with the Regional Government of Catalonia (AATRM).
- Francisco Lupiáñez-Villanueva.
  Lecturer Information and Communication Sciences, Open University of Catalonia.
- Miquel Àngel Mayer.
  Director of Médica Acreditada website, Official College of Doctors, Barcelona.
- Maria Dolors Navarro.
  Assistant Director of the Fundació Biblioteca Josep Laporte.
- Andreu Segura.
  Head of Public Health and Research at the Institute for Health Studies.
- Beatriz Viejo.
  Scientific Editor specializing in health.

Students on Master's Degree in Scientific, Medical and Environmental Communication at Pompeu Fabra University of Barcelona

- Sergio Arroyo, Roser Bosser, Leticia Costas, Marie Czamanski, Helena García, Sonia Liñán, Ana Lozano, Leonardo Medellos, Neus Pavón, Mar Santamaría, Sara Sentís and Cecilia Valenza.

Publications

Bioethics Monographs:

20. *Ethical challenges of e-health*
19. *The person as the subject of medicine*
18. *Waiting lists. Can we improve them?*
17. *Individual Good and Common Good in Bioethics*
16. *Autonomy and Dependency in Old Age*
15. *Informed consent and cultural diversity*
14. *The issue of patient competence*
13. *Health information and the active participation of users*
12. *The management of nursing care*
11. *Los fines de la medicina (The Goals of Medicine)*
10. *Corresponsabilidad empresarial en el desarrollo sostenible (Corporate responsibility in sustainable development)*
9. *Ethics and sedation at the end of life*
8. *El uso racional de los medicamentos. Aspectos éticos (The rational use of medication: ethical aspects)*
7. *La gestión de los errores médicos (The management of medical errors)*
6. *The Ethics of medical communication*
5. *Problemas prácticos del consentimiento informado (Practical problems of informed consent)*
4. *Predictive medicine and discrimination*
3. *The pharmaceutical industry and medical progress*
2. *Ethical and scientific standards in research*
1. *Freedom and Health*

Reports of the Foundation:

4. *Las prestaciones privadas en las organizaciones sanitarias públicas* (Private services in public health organizations)
3. *Therapeutic Cloning: ethical, legal and scientific perspectives*
2. *An ethical framework for cooperation between companies and research centers*
1. *Social Perceptions of Biotechnology*

Ethical Questions:

1. *How to deal with repeat sexual offenders?*

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