

Monographs of  
the Víctor Grífols 25  
i Lucas Foundation

# Ethics: the essence of scientific and medical communication

FUNDACIÓ  
VÍCTOR  
GRÍFOLS  
i LUCAS

4300/1  
14/01/11

Ethics: the essence of scientific and medical communication

25

Monographs of  
the Víctor Grífols 25  
i Lucas Foundation



FUNDACIÓ  
VÍCTOR  
GRÍFOLS  
i LUCAS

# Ethics: the essence of scientific and medical communication

ISBN 978-84-693-7946-2  
Edited by: Fundació Víctor Grífols i Lucas. c/ Jesús i Maria, 6 - 08022 Barcelona  
fundacio.grifols@grifols.com www.fundaciogrifols.org

Monographs of  
the Víctor Grífols 25  
i Lucas Foundation

## CONTENTS

Page

### Presentation

|                             |   |
|-----------------------------|---|
| <i>Victòria Camps</i> ..... | 7 |
|-----------------------------|---|

### Ethics: the essence of scientific and medical communication

|  |    |
|--|----|
| <i>Vladimir de Semir</i> .....                                   | 8  |
| <i>The Quiral Report: trends in medical news reporting</i> ..... | 12 |
| The crisis of the media .....                                    | 22 |
| The crisis of high-quality analytical journalism .....           | 30 |
| The crisis in the social perception of information .....         | 41 |
| The crisis in the access to knowledge .....                      | 45 |
| The internet: a strategic communication tool .....               | 47 |
| More is not always better .....                                  | 52 |
| Communicating in a climate of trust .....                        | 58 |
| References .....   | 62 |

|                                       |    |
|---------------------------------------|----|
| Debate and expert contributions ..... | 68 |
|---------------------------------------|----|

|                            |    |
|----------------------------|----|
| Seminar participants ..... | 90 |
|----------------------------|----|

|                    |    |
|--------------------|----|
| Publications ..... | 92 |
|--------------------|----|

## PRESENTATION

In 2001, the Víctor Grífols i Lucas Foundation organized its first debate on “The ethics of medical communication” to analyse how people operated in the field of medical communication and journalism; how society received information; what the sources of this information were; the influence of experts; and the problems raised by the complex relationship between the world of medicine and health on the one hand, and public perception and public opinion on the other. This event provided the basis for a monograph of the same title, and both the Spanish and English-language versions have been among the most widely read of the Foundation’s publications.\*

Nine years have passed since then, and we felt it was essential to revisit the subject in light of the far-reaching changes in the world of communication, primarily as a result of the expansion of access to information. The new communication technologies have revolutionized the world of journalism in general and the manner in which people access medical and health information in particular. This technological revolution has transformed the relationship between doctors and patients and their relatives. It is impossible to ignore the emergence of social networks, which enable fast and wide-ranging cooperation between members, amplifying the dissemination of information across society.

For this reason, the Víctor Grífols i Lucas Foundation, in collaboration with the Scientific Communication Observatory of the Pompeu Fabra University, organized a second discussion seminar in May 2010 on “The ethics of scientific and medical communication” to provide an up-to-date perspective on this important issue. This monograph brings together the paper presented by the director of the Scientific Communication Observatory of the Pompeu Fabra University, Vladimir de Semir, the debate and other contributions from the experts who participated in the seminar.

*Victòria Camps  
President of the Víctor Grífols i Lucas Foundation*

---

\* *The ethics of medical communication*, Fundació Víctor Grífols i Lucas, 2002. Available at: [http://www.fundaciogrifols.org/portal/en/2/7353/ctnt/dD10/\\_/\\_/5ul/06-Ethics-of-medical-communications.html](http://www.fundaciogrifols.org/portal/en/2/7353/ctnt/dD10/_/_/5ul/06-Ethics-of-medical-communications.html)





# Ethics: the essence of scientific and medical communication

**Vladimir de Semir**

*Scientific Communication Observatory  
Pompeu Fabra University*

Communication has become so vital to our society that Descartes' statement "I think, therefore I am" has now been supplemented by the saying, "I communicate therefore I am." In the current social and historical context, communication is not only an essential tool for any activity, but is also synonymous with the seductive possibility of having a social presence which is at once local and global. Universities, research centres, hospitals, companies, public bodies ... any community, group or individual which wants or needs to present itself to society must communicate not just to support its activities but as a keystone of its very existence. There are very few exceptions to this rule. Whether you are a writer who wants people to buy your books or a multinational pharmaceutical company, informing society is an essential task. This has always been the case, but the communicational dimension of today's society, in which citizens demand explanations with ever greater insistence, means that this need for information has become a vital requirement.

In scientific and medical research, information has become inseparable from the research process itself. Scientific, medical or clinical advances in one area are intertwined with those in others. And the achievements of research teams rely heavily on the knowledge developed by others. While there may have been exceptions to this rule in the past, the complexity of modern research and innovation means that progress is dependent on the transmission of scientific knowledge through the global information network. But scientific development cannot ignore the need to inform wider society. There is universal recognition that the basic responsibilities of today's scientists include the need to communicate their knowledge to the wider public. This responsibility is particularly incumbent upon public and private health centres which promote scientific and medical progress in our society. In this context, information is an essential part of the process of socially justifying our activities, and enables us to take ever more ambitious steps.

The adoption by society of major health revolutions which heralded far-reaching qualitative and quantitative changes in the fight against disease and to increase life expectancy, such as improved hygiene, the use of anaesthesia, and treatment with antibiotics did not require universal consensus because

there were no major ethical problems associated with the new knowledge being applied. However, the challenges faced today are of a different nature altogether and do not brook comparison with those which have gone before. The fourth great medical revolution in the history of humanity is already under way: predictive and genetic medicine which raises the possibility of intervening to determine the biological characteristics which define us as human beings. The ethical problems which derive from the mere possibilities offered by these almost unimaginably powerful new technologies relate not only to the expansion in human knowledge which they represent but also to how we tell society about them, as it is essential that such developments are universally understood and accepted. While, at the day-to-day level, even basic diagnostic measures or therapeutic interventions must be transparent and comprehensible by an increasingly demanding public, at the same time health education depends not only on the medical sphere but also and to an increasing degree on the information which is generated by medicine and science, and how this is transmitted, perceived and absorbed by ordinary people.

The philosopher and anthropologist Georges Kutukdjian, a long-standing advocate of human rights and director of UNESCO's Bioethics Unit, has argued that, in today's historical, cultural, social and scientific context, "ethics should be the essence of communication".<sup>1</sup> And this consideration, which applies to the transmission of all sorts of information, is particularly pertinent to the communication of scientific and medical knowledge. There is no discourse, whatever its purpose, which is truly neutral. According to Kutukdjian, there are three basic conditions to be met when considering ethics as the essence of communication: transparency, truth and trust. These are very difficult conditions to satisfy in the current media context, where there is unprecedented pressure to communicate knowledge which is still being developed, and where any 'truths' represent nothing more than a staging post on the long road from medical research to therapeutic application.

The responsibility for creating certain expectations in society is not sufficiently appreciated by the transmitters of information, whether these are researchers, often motivated by specific, personal interests, or journalists,

whose influence is not always matched by the levels of expertise and judgement required for the task of transmitting specialist knowledge to society. The mass media remain ignorant of the responsibilities they bear as a result of the fact that information — provided by the press, the radio, television and the internet — has acquired ever greater importance not just as a shaper of public opinion but also as the prime means by which society is kept abreast of cultural and educational developments. And this is just the beginning. Humanity faces not just the ethical challenges of scientific and medical knowledge, but also the ethical dilemma of communication. Is our media a source of truth? Are our information providers characterized by transparency? Does the profession of journalism earn our trust? Do institutional communication departments pursue the common good or defend specific interests? Does the internet generate greater access to knowledge or does it serve to obscure the cultural and educational messages received by the general public?

## **The Quiral Report: trends in medical news reporting**

To set these questions within their proper context, we have an extremely useful tool: the *Quiral Report* which since 1996 has been compiled by the Scientific Communication Observatory of the Pompeu Fabra University of Barcelona in partnership with the *Fundació Vila Casas*, and which provides an overview of trends in the reporting of medical and health issues in Spain. Throughout this period, the *Quiral Report* has facilitated analysis of the health-related information received by the Spanish population through the daily press, to gain a deeper understanding of the processes which underpin the published information, and to reflect on the impact of these processes both on society as a whole, and on specific sectors of it.

The *Quiral Report* is based on analysis of the five most widely read daily newspapers in Spain. According to official circulation data, these newspapers are *El País*, *El Mundo*, *ABC*, *La Vanguardia* and *El Periódico de Catalunya* (the study also includes any supplements and magazines distributed with these



publications). The study corpus includes any text on health and medicine, including biomedical research, medical care, public health, the training of health staff, drugs and medical technologies, news relating to health companies and any other issue directly or indirectly related to human health or the health system. The study also includes cartoons, but excludes commercial inserts and advertising supplements.

The *Quiral Report*<sup>2</sup> helps us to analyse the responsibility of doctors, health staff and communicators (journalists, institutional and

corporate communication departments etc.) for the transmission of news, with the aim of seeking to improve the quality and accuracy of information which generates huge expectations among those who receive it and in which, therefore, inaccuracy or sloppiness are simply unacceptable because they may trivialize or distort people's understanding of these issues. And let us not forget that much of today's health education is acquired through the media, which have become vehicles of cultural formation for the general public.

As a result, we must be aware of the educational responsibilities of the media. As Victòria Camps, Professor of Ethics at the Autonomous University of Barcelona and President of the Víctor Grífols i Lucas Foundation, argues, "education in and for the media is clearly necessary and is slowing being introduced in the education system, although not in a particularly satisfactory manner. This task requires that the media themselves take on part of the responsibility for educational work, not only through direct education but also by striving to ensure that the information they provide reflects the values that education is seeking to transmit."<sup>3</sup>



This unique analysis of the medical and health information published in the newspapers and provided by the *Quiral Report* — unique because there is no other such long-term study — has led us to the following conclusions:

**1. The increased press interest in health is parallel to the penetration and expansion of information and communication technologies in Spain**

This effect has been particularly marked due to the occurrence of three circumstances at the end of the 20th century and the start of the 21st which favour the information explosion: an increase in the information issued (more organizations and individuals producing biomedical and health information); increased access (journalists receive information which previously was not accessible); and the growth in demand (the information society entails the “need” of citizens to receive information almost immediately, and in this context the interest in health plays a particularly prominent role).

**2. In recent years, newspapers have included more sections specializing in science or health (usually as a ‘section’ rather than as a ‘supplement’)**

The majority of information on health and medicine continues to be covered in the main newspaper, as has been the case for decades. That is, located in general sections and competing, as a result, with a wide range of news items (natural disasters, social issues etc.). In the final years of the decade under analysis, however, we began to observe a trend towards the creation of specialist sections, not generally published as supplements but rather as sections inside the newspaper at the same level as others (politics, international news, the economy, culture etc.) and which may be published daily or weekly. However, it is hard to identify firm trends in this regard, with supplements appearing and disappearing somewhat irregularly during the study period. As a result, it is impossible to predict the future of science and health supplements in the Spanish press.

**3. Health is covered primarily from a news perspective, but without the contextualization or expert consideration provided by the opinion and analysis pieces which often address other issues**

Opinion and analysis pieces represent a very small percentage of the corpus in comparison with news reports. In the first years of the study, a slight increase in opinion and analysis pieces was observed, but in the second stage, particularly in recent years, this trend was reversed.

**4. Readers, authors and publishers are interested in different issues. Readers are primarily interested in articles about daily care issues; writers, in biotechnology; and publishers, in epidemics**

The analysis of letters to the editor, editorials and opinion pieces reveals three different profiles with respect to the issues addressed in different types of text. Given that these three types of text represent, respectively, readers, newspaper editors, and the community of experts, these differences are paradoxical to say the least.

**5. The letters pages can be used strategically by readers to address those with political responsibility for the health system**

Analysis of the impact of a letter from a cardiologist reporting the deaths of a number of patients while on the waiting list for operations shows how a letter can spark a dramatic response in the media and, as a result, have a specific impact on the actions of those with political responsibility for the health system. This type of action is what is known in the English-speaking world as *media advocacy*, or the strategic use of the media not so much to reach the general public as to communicate with politicians and decision-makers. In this respect, one of the cases analysed, the campaign against tobacco, offered a clear example of the strategic use of the letters pages.



**6. Although the press has addressed a wide range of issues during the last ten years, the reality is that it focuses on a few high-profile issues, and these in turn set the social agenda**

This means that reporting concentrates on specific themes or issues which are not always representative of the realities of the health sector, but which instead acquire a life of their own as the object of journalism. This concentration provides an image which has little to do with the overall realities of the medical and health sector. The result is a distorted image which ignores some concerns and magnifies others. While this reductionist view is not exclusive to the health sector and the same occurs in many other areas, distorted information in this area can lead to changes in behaviour and habits, with potentially serious consequences.

Over half of the material published during the first decade of the study (55.32% to be precise) focused on just ten issues: the healthcare system, five high-profile illnesses (AIDS, cancer, anorexia, diabetes and heart disease), biotechnology (cloning, stem cells, genetics, genome mapping), epidemics and food crises, caring for personal health, tobacco, medicines and the pharmaceutical industry, reproduction and sexuality, drugs and, finally, euthanasia. In this context, effective media education is essential if Spanish society is to increase its capacity to interpret information and take decisions.

**7. Decisions about what is newsworthy or not in the health sector are governed by the same criteria as other spheres: news values, production processes and relations between communication agents**

Research into the media has identified a range of explanations as to how the news is produced and the *gatekeeper* (or news selection) function of the press, although it seems likely that in reality a combination of these different explanations or theoretical approaches is involved. In the case of health, study of the key issues allows us to conclude that it is subject to the same processes as those which apply elsewhere in the media. In the health sphere, the different theoretical approaches are expressed in the following ways:

- a) The news values or inherent characteristics of the events themselves, which increase or reduce the likelihood of these being reported.
- b) The influence of production processes and journalistic routines. As a result, in addition to the characteristics of different issues, the way the media is organized may determine what is or isn't news.
- c) The structure of relations between different information agents. The more or less organized role of the different actors who intervene in the information process is another determining factor.

**8. Observation of the existence of two distinct templates for media coverage of medical and health issues — acute and chronic — raises questions about how this in turn influences the general public**

The analysis of variables such as the evolution of information over time, the prominence given to the news item in the newspaper, the degree to which the information is developed, and the more or less frequent use of expert sources has led to the identification of two distinct templates for media coverage, which we have called the *acute template* and the *chronic template*, respectively. The existence of these two templates is not an empty question, because each is received differently by readers and, therefore, has a different impact on public perception and opinion.

The high media impact of the acute template means that the issues which are covered using this model are more visible and have a higher profile in the media agenda (and therefore in the social agenda). Paradoxically, these high-profile reports based on the acute template rarely contain detailed information which is contextualized and subject to analysis, in contrast with issues reported according to the chronic template. By contrast, issues covered using the chronic template are more consistently represented throughout the year, but also accorded less prominence. The issues which follow this template have a gradual impact, particularly among those readers who go beyond the headlines or the front page and those who take a particular interest in biomedical and health issues.

***9. The existence of three modes of relationship between public bodies and the media — pressure, alliance and utilitarianism — suggests different types of influences on how events develop***

The pressure model arises from the fact that media coverage provides an opportunity for criticizing government action. The journalist reports the opinions of experts, but also intervenes with comments or clarifications which reinforce the critical tone. Under the alliance model, public bodies and the media work together to promote healthy behaviours. The media prepare the ground for the application of new actions in the health sphere (laws, regulations, campaigns) and disseminate messages from the authorities, making clear their support for them. In a third type of relationship, utilitarianism, the media limit themselves to disseminating information issued by the authorities, but without clearly coming out either in favour or against it.

***10. Information sources are concentrated in a few sectors and in specific individuals. Journalists use their sources to lend credibility to their work, while the sources use the media to gain visibility for the information they wish to publicize***

The main information sources are drawn from the science and health sectors, and the political-administrative sector. Journalists use the first for credibility, the voice of expert opinion, while the second speak on behalf of official power. The pharmaceutical industry and, to a lesser degree, other companies not linked to the pharmaceutical sector, are also a source of information, although they are mentioned very rarely as an overall proportion. Finally, it is important to note the role of civil society as an information source, whether in the form of associations (NGOs, patients' associations, consumers' associations etc.) or as individuals. The presence of this sector as an information source has grown steadily during the period covered by the *Quiral Report*.

***11. Scientific journals as an information source support journalists because they provide new and accurate information; however, they can be a two-edged sword***

When a scientific investigation makes the transition from specialist journals to the daily press, some of the news values, such as novelty, proximity and relevance for the readership, must be adapted to reflect the new context. At the same time, the classical 'Wh-' words of journalism (what, who, how, when and why) take a particular form in scientific research: the publication of the study becomes in itself the newsworthy act (the 'what'), while the date of publication constitutes the 'when'.

Journals are a good information source for the media, offering as they do a guarantee of credibility. However, journals are also eager to be cited in the mass media as this raises their visibility and, over time, increases their impact in the scientific community. As a result, the commitment to rigour, transparency and objectivity on which the peer review system is based — and which is the foundation for the credibility of scientific journals — is often compromised when writing press releases. And this may have disastrous consequences, given the impact of press releases on the media, and the impact of the media on the rest of society.

***12. The internet has changed many aspects of the relationship between citizens and health information and the management of their own health, including the facilitation of participation in patients' forums and their interaction with the press***

Throughout the study period, the press has gradually adapted to a series of changes arising from the introduction of information and communication technologies. The information provided on newspaper websites is updated continually, new multimedia formats are introduced, and websites themselves have become increasingly interactive. At the same time, the internet has given greater voice to civil groupings such as patients' associations. Patients are shifting from a passive to an active role in which they demand the right to





participate in the decision-making process, and particularly in decisions regarding treatment and monitoring.

***13. Women have a smaller role than men in public information about health, both at the level of taking editorial decisions at newspapers and in terms of their participation as information sources (although this is gradually changing)***

In the newspapers studied, editorial decisions were in the last instance taken by men, with women only scantily represented in senior positions. At the same time, at the end of the study period (2006) individual information sources in health issues remained predominantly male, although the gap has narrowed in recent years. While, between 1997 and 2001, for every woman quoted as an information source, four men were cited, by 2006 this ratio had risen to one in three. Although the imbalance between male and female roles in health information is often presented as inevitable, it is possible to change

this. As a result, the report puts forward a series of recommendations designed to address this gender bias.

***14. Caricatures and cartoons provide an opportunity for overcoming conventional barriers and expressing opinions about health issues with the same satirical edge applied to any other news issue***

Cartoons in the Spanish press generally form part of the analysis and comment section. They usually refer to political events, the decisions of government and local authorities, and social attitudes to issues which are in the news. In general, cartoons relate to high-profile topics which are covered on the basis of the acute template. Cartoons are not only a means of expressing an editorial opinion, but also serve as a form of criticism by taking a satirical view of situations, public figures or ordinary people. Through cartoons, the press provides a space for the kind of direct, hard-hitting criticism, protected by a veneer of humour, which is not usually found in daily newspapers. And a picture is often worth a thousand words in terms of its impact on public opinion.

***15. Case studies have helped to clarify the communication process in health and biomedical issues***

- The analysis of **epidemics** shows that a communication strategy can be a determining factor in deciding how the media transmit information. These are not just theories. Communication strategies for crisis situations are now being developed on the basis of scientific evidence drawn from actual experiences.
- In the case of information about **smoking**, the analysis has helped to explain a change in how Spanish society perceives one of the most important public health problems. At the same time, the changing roles of the key players (anti-smoking groups, individuals, the state and, finally, the media) reveal how they influence each other, and the power of information.

- The study of media coverage of **biotechnology**, in addition to showing how this knowledge area has developed during a period of profound change, has also made it possible to identify the range of different discourses present. The identification of different discourses — economic, political, ethical, religious, scientific — helps to make clear that science and medicine are not isolated and neutral but develop in and for society.
- **Anorexia** has revealed the complexity of many mental illnesses. This complexity is marked by the shifting emphasis on social or biological factors as determinants of the illness. And by the hypocrisy of a society which, while recognizing that adolescents are victims of fashion and of the media, shows no qualms about mistreating and harassing famous sufferers (models, actresses, aristocrats).
- In the analysis of **cancer** it was found that the information about this illness has often been trivialized, and that this continues to be the **case**. The large number of carcinogenic and anti-carcinogenic substances reported during the last ten years bears more in common with a collection of curiosities than with the result of years of effort by scientists to investigate the causes and treatment of one of the illnesses which most concerns humanity. The search for the scientific evidence to underpin such reports is a frustrating one, as is the lack of follow-up or contextualization of such information.
- Finally, the analysis of **AIDS** has illustrated a change in focus. From the optimistic, locally based discourse of the late 1990s to the more committed, global discourse which emerged in 2000, the report identifies a range of voices and opinions, and provides historic evidence of the development of this illness.

## The crisis of the media

Today, almost 15 years after the birth of the *Quiral Report*, based on traditional printed newspapers, we find ourselves at a critical junction: the media, and the long-standing advertising model which underpinned their existence

and growth for over a century, are immersed in the difficult process of adapting to the information society and internet communication. The communication system as a whole has become less stable. The influential journal *Nature*<sup>4</sup> has argued that science and medicine must see public communication as a key part of its activities, and that scientists and medical researchers should use the tools offered by the blogosphere and web 2.0 technology to directly inform the public, with the aim of offsetting the serious decline being suffered by traditional scientific journalism, which is under attack in the mass media as a result of reductions in the number of editorial staff, and cuts in the amount of space dedicated to such issues. Society as a whole and in the way it accesses knowledge is undergoing a period of change as a result of the powerful tools provided by information and communication technologies, primarily the emergence of the internet, in our lives.

The world of news reporting, in particularly, is experiencing a sea change. The usual way in which people have accessed information — primarily through the press, radio, TV and, more recently, free newspapers — is being shaken by new channels and formats — websites, blogs, podcasts, Google News, Facebook, Twitter etc. — and by a gradual change in the public's attitude to how they consume information and culture in general. The use of the word *consume* in this context is deliberate, reflecting as it does a profound change in social habits in which the traditional role of journalism as an intermediary between those who know and those who do not is giving way to that of the content provider. And at the same time, what is known as citizen jour-





## nature Breaking the convention?



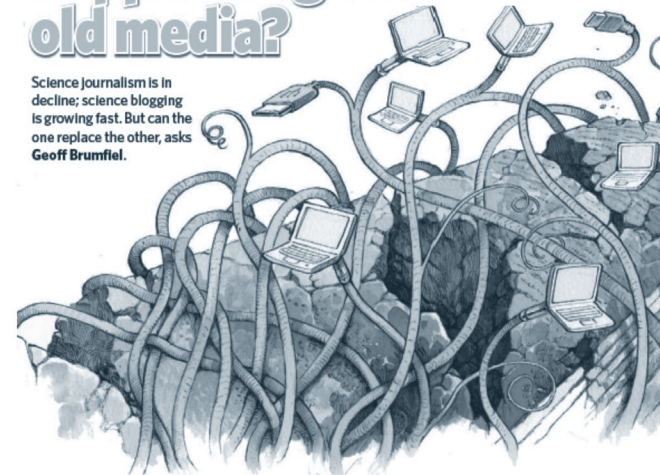
nalism — expressed through the powerful medium of social networks — is emerging forcefully and changing the rules of the game: we can all be both providers and recipients of information.

The epicentre of the earthquake is a long way from the centre and is not very obvious to the general public, which tends to be passive and uncritical with regard to the world of information and culture. It should also be noted that the traditional giants of the media world have been trying to prevent the impact of these developments, primarily because they failed to see the approaching technological, economic, social and cultural changes, and most of them reacted slowly and clumsily. So long as the flow of money from advertising budgets continued, there was no clear incentive to change: if fewer newspapers were sold, the figures were disguised by block sales to support advertising, and above all the newspaper was recast as a vehicle for the sale of other products in the form of promotions. If the television audience was not sufficient to attract large advertising campaigns, then what could be easier than dumbing down the content even further.

While this trend may have delivered short-term financial gains, it is far removed from the traditional aim of seeking to create a loyal base of readers (now redefined simply as purchasers or consumers) by offering high quality

## Supplanting the nature old media?

Science journalism is in decline; science blogging is growing fast. But can the one replace the other, asks Geoff Brumfiel.



information in the main section and supplements, a commitment which is constantly weakening. As a result, we have moved from the model of the newspaper as the provider of a wide range of high-quality information to what one might term the *newspaper-bazaar*. And there is no shortage of examples of the trend in TV.

There is something of a tendency to assume that the emergence of information and communication technologies lies at the root of the crisis in the traditional media, but the reality is that this is not solely attributable to the internet revolution. According to a report produced by Gartner Inc.,\* “newspapers have not done enough to make the most of the social potential of their readers.” The analysts at Gartner recognize that newspapers face falling circulations and declining incomes as a result of competition from digital sources, but they also attribute the problems to the fact that newspapers have failed to

\* Gartner, Inc. is one of the world’s leading information technology and research advisory companies, with 1,200 researchers and consultants in 80 countries: [www.gartner.com](http://www.gartner.com).

capitalize on their greatest resource: their readers. They have failed to adapt to their needs and interests in a changing world.<sup>5</sup>

Although the changes may not be too obvious to the general public from day to day, if we look carefully we can see that there is a constant trickle of problems and crises. At the start of May 2007, Hearst Co., the publishing company which owns the influential *San Francisco Chronicle*, announced that it was making a quarter of its editorial staff redundant in response to the newspaper's financial problems, and this despite the fact that the paper has adapted well to the internet era. Its website (SFGate.com) is one of the ten most visited news sites in the United States, despite which it does not generate sufficient advertising income to make up for losses elsewhere as a result of changes to how people access the news. Many other written and audiovisual media have gradually reduced their offering over recent years, closing sections in areas such as science and the environment,<sup>6</sup> on the one hand, and converting medicine sections and supplements into pages and magazines dedicated to "health and living" with a significant product advertising element, on the other.<sup>7</sup> Indeed, these are commercial products driven not by editorial staff but by marketing departments. One statistic illustrates this process very clearly: a couple of decades ago, 150 of the leading newspapers in the United States had science sections; today the figure is just 20.

Neil Henry, Professor of Journalism at the University of Berkeley (California), writing in the *San Francisco Chronicle* shortly after the announcement of staff cutbacks, in an article titled "The decline of news"<sup>8</sup> argued that:

"When journalists' jobs are eliminated, especially as many as *The Chronicle* intends, the product is inevitably less than it was. The fact is there will be nothing on YouTube, or in the blogosphere, or anywhere else on the Web to effectively replace the valuable work of those professionals. I see a world where the craft of reporting the news fairly and independently is very much endangered; and with it a society increasingly fractured, less informed by fact and more susceptible to political and marketing propaganda, cant and bias. I see a world in which the pursuit of truth in service of the public interest is declining as a cultural value in our society amid this technological tumult; a world where professional journal-

ism, practised according to widely accepted ethical values, is a rapidly diminishing feature in our expanding news and information systems, as we escape to the Web to experience the latest "new" thing. I see a world where corporations such as Google and Yahoo continue to enrich themselves with little returning to journalistic enterprises, all this ultimately at the expense of legions of professional reporters across America, now out of work because their employers in "old" media could not afford to pay them."

And the problem can be much more serious. Some analysts go further, arguing that this gradual impoverishment of the information in the mass media will have disastrous consequences for the cultural level of our society, despite apparently creating access to knowledge. It is clear that use of the internet can only be truly useful to a population which already has sufficient education to take advantage of it as a source of real knowledge.<sup>9</sup>

In March 2009, "in response to decreases in science coverage by the media," a group of leading universities and research centres in the United States and Canada decided to create *Futurity*, a science news portal which offers information direct from producers (the scientific, medical and environmental

**FUTURITY** Discover the Future  
NEWS FROM LEADING RESEARCH UNIVERSITIES

EARTH & ENVIRONMENT HEALTH & MEDICINE SCIENCE & TECHNOLOGY SOCIETY & CULTURE

**Marveling over 'molecular chicken wire'** 11.22.2009

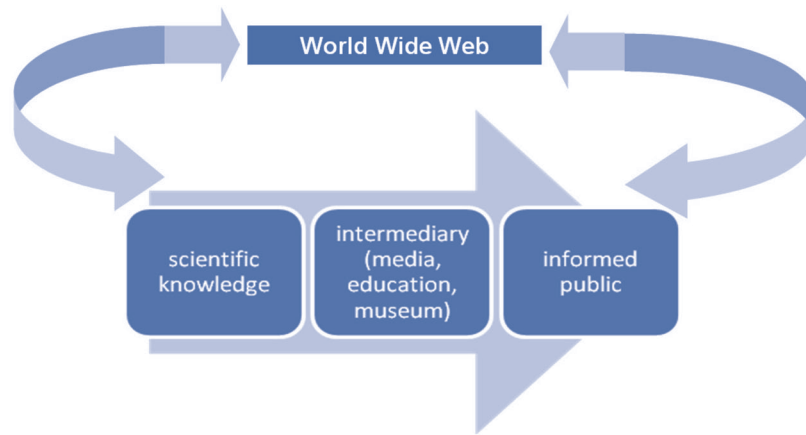
TOP STORIES | NOVEMBER 18TH, 2009 | COMMENTS

**VANDERBILT**—The hottest, thinnest, toughest new material in physics and nanotechnology is graphene: a remarkably flat molecule made of carbon atoms arranged in hexagonal rings much like molecular chicken wire. [Read more](#)

**Futurity in the News**  
On the Media (NPR)  
October 9, 2009  
Direct to Consumer Science  
Science departments at newspapers everywhere are shrinking. One outlet that aims to help fill the coverage gap is Futurity.org, a new website that lets scientists publish their findings directly to the public.  
[More headlines...](#)

© Calvin Davidson, British Carbon Group





community) to the general public.<sup>10</sup> *Futurity*, which today has expanded to include more organizations, including institutions in the United Kingdom, provides a clear alternative to the traditional communication of scientific knowledge through journalists. In other words, scientists can now *bypass the media* when sharing information with the general public, while readers can search for information provided directly by the sources.<sup>11</sup>

This portal is an example of the specific changes taking place in the social communication of science, medical and environmental knowledge. This approach is becoming increasingly common among knowledge producers, allowing them to communicate with the general public directly through the various channels offered by the internet, without the need for the media to act as intermediaries. The potential for such initiatives is probably very great, given the high credibility of the scientific and medical community among the population (at least in general terms) when compared with the gradual decline in the trust placed in journalism. *Futurity* sets out its aims and the rationale for its existence in the following terms:

Why *Futurity*? Why now? The way people share information is changing quickly and daily. Blogs and social media sites like YouTube, Twitter, and Facebook are just a taste of what's to come. It will be easier

than ever to share content instantly with people around the globe, allowing universities to reach new audiences and engage a new generation in discovery.

Equally significant has been the recent decline in science and research coverage by traditional news outlets. For decades, universities have partnered with journalists to communicate their work to the public, but that relationship is evolving. At the same time, research universities are among the most credible and trusted institutions in society, and now have the ability to deliver their news and information directly to readers.

In an increasingly complex world, the public needs access to clear, reliable research news. *Futurity* does the work of gathering that news. Think of it as a snapshot of where the world is today and where it's headed tomorrow. Discover the future."

The example of *Futurity* illustrates a more general trend which raises the following questions:

1. If the public can access information first-hand (and free of charge), what role is there for the media?
2. Do the media offer added value for the user as information providers?
3. What reasons do scientists and doctors have for sharing their information with the public?
4. Is this extra effort justified for the world of science?
5. Does traditional journalism bear some of the blame for the proliferation of this *bypass*?
6. Is it possible that the quality of information will suffer as a result of the new way in which it reaches the general public?

It is now possible for the public to directly access the source of information they are interested in. However, readers also need to be aware of the new rules of the game. Initiatives such as *Futurity*, which serves to illustrate this trend, may lead to a genuine increase in society's scientific knowledge or may pursue other goals which primarily benefit the interests of knowledge producers themselves. For example, one quite common goal which, while legitimate, is not always transparent, concerns the fact that an initiative such as this may

also seek to promote universities and research centres (a new channel for institutional communication). At times, the scientific, medical or environmental organization behind the site is seeking not only to promote itself but also to find new customers, improve its social image, disseminate information for very specific purposes (e.g., to raise additional funding) etc. The user has direct access to the information, but the reasons for providing the information are not always clear. There is no such thing as absolute objectivity in journalism, but nor is there in the world of institutional communication.

While recognizing the importance of an initiative of this sort, which seems set to become an essential source of scientific information on the internet, we must also be alive to the danger that, along the way, we will lose the critical, analytical, independent journalism which assesses and contextualizes the information provided by institutional communications departments. Indeed, Yahoo and Google News have already announced that they will use *Futurity* as a major source of the news they distribute.

## The crisis of high-quality analytical journalism

Will high-quality analytical journalism really be affected? This is quite possible, but we should not forget that very often scientific journalism has contributed to its own downfall through the lazy use of press releases and the almost verbatim transmission of information supplied by the communications departments of universities, research centres and, above all, certain highly influential journals such as *Nature*, *Science* or *The Lancet*, among others.

Indeed, scientific journals have been and continue to be the most common source of news information about science and medicine.<sup>12</sup> For decades, scientific advances were presented at academic conferences, giving such meetings a key role in the news generation process. However, the “newsworthiness” of conferences gradually declined as scientific journals became the central means of communication within the scientific community. At the same time, journals have actively sought media attention, and to gain this they have



resorted to a range of different tools, the most common of which is the issuing of weekly press releases. In these releases, strictly scientific language is decoded and replaced by more everyday language, while the information itself is cut down so as to make it easier to digest and more “newsworthy”. The effectiveness of press releases, supported by the multiplier effect of information and communication technologies such as the internet and email, has been spectacular. This means that journals have the capacity to contribute to enriching the

culture of society in scientific matters, as a result of their strategic role in linking the scientific community and the mass media. However, neither the press releases nor the links they have established with the media have enabled journals to maintain the same levels of rigour, transparency and objectivity which, in principle, characterize their relationships with researchers and the scientific community in general. Too often the desire to create an impact has affected how scientific information is communicated to journalists and, therefore, how this information reaches society. There is also another important question: is the ambition to make an impact in the media affecting the scientific excellence of journals themselves?

Press releases are, therefore, a very valuable tool for journalists and scientific journals alike, but they are also a two-edged sword. When the issuing of press releases by scientific journals began to become general practice thanks to the opportunities offered by email and the internet, a research study conducted by the Scientific Communication Observatory-Pompeu Fabra University<sup>13</sup>

found that there was a strong connection between the selection of articles included in press releases and the news items published in the media. There is even a clear correlation between the order in which articles are identified in press releases and their likelihood of being covered in the press: those which are cited first or second are more likely to be covered than those in third or fourth place, and these are in turn more likely to be covered than those in lower positions. The influence, therefore, of these releases on the selection and publication of scientific news in the media is undeniable and decisive.

This study of the relationship between press releases and publication in the mass media has been followed by others, such as that which showed that press releases contain features which would be unacceptable in a scientific article and which can only be explained by the need to make the media's job easier.<sup>14</sup> These press releases do not explain the limitations of the studies or the role of the industry in funding them, while the data is often presented using formats and headings which tend to exaggerate the reader's perception of the importance of the results. In general, press releases issued by journals magnify the value of scientific findings and apply criteria for evaluating and ordering information which are closer to those of journalism than to those of professional scientific communication. As a result, the commitment to rigour, transparency and objectivity on which the peer review system is based — and which is the foundation for the credibility of scientific journals — is often compromised when writing the press releases which are sent out to journalists.

In recent years people have begun to question the unthinking use of the conveyor belt system which makes uncritical use of press releases to transmit information to scientific and medical journalism. This process was defined by L.K. Altman — the leading medical journalist at *The New York Times* — as encouraging a “lazy journalism” which promotes “homogeneous information”.<sup>15</sup> The fact is that, to a large degree, the scientific and medical news cycle has operated in this way for many years, although this effect is amplified greatly by the opportunities provided by the internet.

As *The New York Times* argued in an article prompted by the scandal of the human cloning claims made by South Korean scientist, Hwang Woo Suk:



“Now news organizations say they are starting to look at the science journals a bit more sceptically... and also maybe [require] some new protocols between scientists and journalists.”<sup>16</sup>

Richard Smith, the editor of the *British Medical Journal* for 13 years, reflected as follows on the relationship between the scientific journal and the media: “Some would also argue that journals have an unhealthy relationship with the mass media. Indeed, they might be degenerating to a branch of show business. [...] there is no doubt that coverage in the mass media is good for journals both in prestige and in business terms. All the major journals put out press releases [...] and are disappointed if an issue does not receive any coverage [...] But are journals debasing ourselves in pursuit of publicity?”<sup>17</sup>

In recent years, many other analysts of scientific communication have criticized this way of doing things. In 2006, Vincent Kiernan — associate dean at Georgetown's School of Continuing Studies and a regular contributor to *Chronicle of Higher Education* — published *Embargoed Science*, a hard-hitting criticism of the embargo system under which information is provided to mainstream journalists prior to its publication in specialist journals, subject to a commitment that it will not be revealed before it appears in the journal in question. This is the basis of the current relationship between scientists, scientific journals and the press.<sup>18</sup> Journal editors use this system as a marketing tool to achieve maximum publicity for their publications. The





control of information by means of an embargo creates an impression of immediacy which is actually misleading. The hidden idea which governs the press embargo is a restrictive mechanism which has nothing to do with promoting science in the press and to the public. The editors of scientific journals have, to some degree, assumed the power to decide which journalists have privileged access to the information and which will not.

Kiernan concludes that this system is clearly against the public interest. The effect of embargoes is that journalists highlight the work of some medical and scientific research centres and not others, even when the

latter are geographically or culturally closer. They are artificial, sustain the work of poorly qualified journalists, and often focus attention on science which is of questionable reliability. They prevent journalists investigating science in the same way they would investigate any other social institution, reducing their capacity for analysis. Richard Horton, editor of *The Lancet*, argues that the practice of embargoing suffocates competitive journalism and favours the publication of scientific and medical news items which lack any critical content. The constant flow of press releases distracts journalists from the task of taking a critical approach to their work. This “pre-packaged journalism”, remote-controlled by embargo, should be absolutely anathema for those who resist attempts by external powers to influence their work. It is strange that scientific journalists surrender power to these organizations.<sup>19</sup>

In the last World Conference of Science Journalists, held in London in June 2009, there was a round table discussion of the embargo system. The conclusion reached by many of those taking part was that the embargo system con-

verts many of them into advertising agents, imposing uniformity on science reporting across the globe. Vincent Kiernan himself advised journalists, “It’s time to walk away from the embargo. Just walk away.”<sup>20</sup>

Are journalists prepared to manage this sort of information? Can the public really interpret and assimilate the information offered by the media so quickly? After conducting an extensive survey, researchers at the School of Journalism at the University of Missouri concluded that the majority of journalists had not received essential training in health issues to adequately handle specialist information in medicine and health.<sup>21</sup> According to this study, in which journalists and readers of 396 newspapers and magazines in the United States were interviewed, it is clear that journalists potentially have a very important role in neutralizing the effects of poor “health literacy” in US society. *Health literacy*, as defined by the American Medical Association, is “a patient’s ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions”.

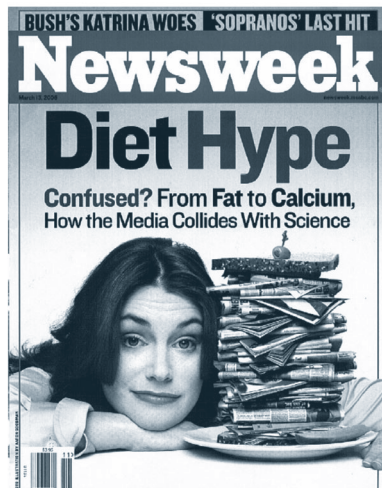
Of the journalists interviewed, only 18% possessed specialist health training. The study notes that “many journalists have difficulty maintaining an appropriate balance between the scientific rigor of the information and overly simplistic recommendations.” Technical terminology and, above all, the ability to handle data and statistics are essential when providing effective health information, but the comprehension of such data and statistics is an almost insurmountable challenge for many people, journalists included. This problem is strongly related to the general deficit in mathematical culture. According to a report produced by the United States Department of Education in 2007, numeracy is a serious problem in the United States. Only 39% of students in that country are at or above the competency level, and without this essential or minimum mathematical knowledge, it is very difficult to understand health information properly.

This situation gives rise to significant problems, such as an inability to search for an appropriate treatment, medication errors and, in general, a serious inability to understand instructions related to health education. “We must actively seek ways of improving health coverage, and must recognize the importance of the media in improving public understanding of quality of life,

as a complement to information issued directly by the health services,” argues the University of Missouri study, which also highlights “the danger that the media may give strength to myths about health.”

The analysis of health and medical information also includes the following worrying conclusions: daily news about treatments, tests, diagnosis, products and procedures can have a profound — and perhaps harmful — effect on health consumers. Journalists do not usually discuss costs, the quality of evidence, the existence of alternative options and the absolute magnitude of potential benefits and drawbacks, among other key elements of good public health education.<sup>22</sup>

There are many examples of the difficulty of adequately handling medical and health information in the mass media. Regardless of whether or not the media organization has specialist journalists and of the professional training these may have received, setting health and medical information in the proper context entails specific problems not encountered in other areas, primarily because of the expectations to which it gives rise. Any news item about an innovative treatment, even if only at an experimental or preliminary phase, causes additional anxiety in patients and their families. The uncertain or provisional nature of any scientific process, which, by its very nature, is always subject to revision, is difficult to communicate in a mass media setting. Often, contradictory messages derive both from the development of scientific and medical knowledge itself, and from the applications of such knowledge. Medical studies of nutrition and healthy behaviours are a frequent source of controversy, of which the following are examples:



Newsweek highlighted the problem in a cover story:<sup>23</sup> “Diet hype: how the media collides with science: the excess

of health news creates general confusion about diets and nutrition. News headlines are incapable of capturing the complexity of scientific research.”<sup>24</sup>

One doesn’t need to go into too much detail to understand the difficulty of transmitting information which starts out as complex science and is destined for the general public in the simplified form of a news story. The final result tends to be difficult to understand, and is frequently contradictory and trivial.

Media coverage of the H1N1 influenza virus also gave us a lot to think about, aside from the actions of the World Health Organization (WHO), criticized as it was by many experts and forced to reconsider its future response to such situations. A mere four days after the first information about the possible emergence of a new strain of flu virus in Mexico, a Barcelona newspaper — and this is just one example of many I could choose — ran the front page headline, “Contagion in Barcelona”<sup>25</sup>. The impression it gave was that people were dropping dead on the streets of the city! However, as is usually the case — except in the tabloid press — the full-length report on the issue inside the paper was far more balanced and rigorous: “The daily reports on the rapid spread across the world of the so-called Mexican flu virus brought an important new development: six cases have now been confirmed in Catalonia, one of whom is a man who had not travelled to Mexico, making him the first officially reported case of indirect contagion in Europe. This case is particularly important because it may have played a decisive role in the WHO’s decision to raise the



pandemic risk alert to level five (on a scale of one to six), corresponding to a situation where the virus is known to have been transmitted from person to person in at least two countries. The decision by the WHO, whose director general, Margaret Chan, announced that a pandemic can be considered “imminent” and urged countries to activate their own action plans, will mean, among other measures, greater control of passenger movements. Only hours before the WHO announced its decision, Spain’s Health Minister, Trinidad Jiménez, and Catalonia’s Regional Health Minister, Marina Geli, had confirmed the presence of the virus in Catalonia. Geli explained that, following the WHO’s decision to activate phase four of the pandemic alert, the review of all people close to patients deemed suspicious became compulsory, and this led to the discovery that the boyfriend of one of the patients who had travelled to Mexico had also contracted the H1N1 virus. The man, from Barcelona, has not been hospitalized.”

Some readers reacted immediately to the front page headline of the newspaper’s website:

- “Great title: “CONTAGION IN BARCELONA”; Couldn’t you be a bit more alarmist? Why not include a photo of a grave? Every day you get a bit more sensationalist ... What a terrible paper ...”
- “Stop getting people worked up. It’s not that serious!”
- “Such an alarmist headline when the article itself reveal that the individual isn’t even in hospital. I think we deserve a bit more respect.”
- “I’m not sure which causes more alarm: the fact that the virus has been caught by somebody who hasn’t been to Mexico, or the size of the headline in *El Periódico*. I really think this creates more alarm than the news itself, particularly if we compare it with the reassuring words of the national and regional health ministers. Next time, please put the headline in a font size which more closely reflects the importance of the news.”
- “In 2006, 100,000 people died of cancer in Spain. Let’s look at this from a different perspective.”
- “Congratulations: the human race is suffering from the worst virus in its history; information overload.”

Le Monde

Chronique Franck Nouchi

## Grippe A, la première pandémie télévisée

**V**ous aimez le débat sur la taxe carbone, vous allez adorer celui sur la grippe A. Il y a les partisans du vaccin, ceux qui défendent l’idée d’une utilisation des médicaments antiviraux à titre préventif, et ceux qui pensent que, comparée aux grandes pandémies responsables de plusieurs centaines de milliers de morts, la grippe A est de la gno-gno-te. Reprenons. Il y a dix jours, dans *Le Monde* (daté 30-31 août), la directrice générale de l’Organisation mondiale de la santé (OMS), le docteur Margaret Chan, expliquait que le virus H1N1 « voyage à une vitesse sans précédent, inédite. En six semaines, il parcourt la même distance que d’autres virus en six mois ». Cette spécialiste renommée de santé publique prévenait : « Jusqu’à 30 % des habitants des pays à forte densité de population risquent d’être infectés ».

Dimanche, dans « C politique » sur France 5, Roselyne Bachelot, reprenant à son compte les recommandations de l’OMS, détaillait son plan, en particulier vaccinal. Le lendemain matin, le professeur Marc Gentilini, ancien président de la Croix-Rouge, était l’invité de la matinale de France Inter. Changement radical de point de vue : « Les décideurs politiques sont victimes de la pression exercée par les spécialistes réputés des maladies infectieuses, les responsables de l’OMS, « pour n’en avoir pas fait suffisamment au moment de l’épidémie de sida, en font trop » » cette fois-ci. « Le fameux principe de précaution, ajoute M. Gentilini, n’est pas fait pour protéger les décideurs mais pour protéger la collectivité ».

« Ce milliard et demi d’euros qui va être dépensé pour lutter contre l’épidémie de grippe A en France, ne pourrait-on pas l’utiliser plus efficacement à autre chose ? », demande-t-il, rappelant que, pendant que 2 000 personnes mourraient dans le monde des suites de la grippe A, plus de 500 000 décédaient des suites du paludisme. « Gouverner, est-ce envisager le pire ? », lui demande Nicolas Demorand. « Je ne le crois pas, répond M. Gentilini. Il faut chercher l’équilibre. Pêcher par défaut est une faute grave. Mais par excès aussi. » M<sup>me</sup> Chan le disait elle-même :

« Pêcher par défaut est une faute grave. Mais par excès aussi »

Marc Gentilini  
ex-président de la Croix-Rouge

« C’est la première fois dans l’histoire que l’on voit une pandémie évoluer sous nos yeux. » Lundi soir, le sujet principal des journaux télévisés de TF1, France 2 et M6 était consacré aux quelques fermetures de classes survenues ces jours-ci en France du fait de la grippe A. Face à David Pujadas, Marc Gentilini, une nouvelle fois, faisait entendre un son de cloche discordant. On finissait par se demander si, dans un tel contexte d’incertitudes, la retransmission télévisée, en quasi-direct et avec toutes les approximations que cela suppose, de l’avancée du H1N1 était compatible avec la sérénité nécessaire aux processus de décision en matière de santé publique. ■

On finissait par se demander si, dans un tel contexte d’incertitudes, la retransmission télévisée, en quasi-direct et avec toutes les approximations que cela suppose, de l’avancée du H1N1 était compatible avec la sérénité nécessaire aux processus de décision en matière de santé publique. ■

- I think it’s an overreaction to activate this level of alert due to one indirect contagion in Barcelona. What does indirect mean? The person who caught it had been in contact with someone who already had the virus, hadn’t they? So surely contagion is logical, whatever the situation?”
- “I’m sure far more people have died from the common cold in the world year this than from this recently detected virus.”

A few months later, the French newspaper *Le Monde* made the following assessment of information about the new flu strain:

“Swine flu, the first televised pandemic: we must ask whether, in a context of such uncertainty, virtually live coverage of the progress of the H1N1 flu virus, with all the approximations that implies, is compatible with the calmness necessary when taking decisions about public health.”<sup>26</sup>

The Winter 2009 issue of *Médiatiques* (page 40), a Belgian journal for the study and critical analysis of media discourse published by the Observatoire du Récit Médiatique of the Communication Department of the Catholic University of Leuven, dedicated a lengthy piece to pub-



lic communication of swine flu: “Surprising, disturbing, worrying, catastrophic, pandemic... When swine flu appeared, the media response was alarmist, seemingly in preparation for the worst. However, does information about the virus necessarily entail an explicitly alarmist discourse? [...] In France, H1N1 flu was the most common health issue in the media, as shown by analysis of the TV news, where it accounted for 63.82% of health-related reports between July and September 2009. This raises the question as to what role the French media perform: do they simply describe events, or do they initiate debate?”<sup>27</sup>

It seems clear that there is little scope for coverage of a new illness that does not involve transforming sensible concern into unfettered alarm if, day after day and week after week, the news starts with a body count, as the majority have done in this instance.

The sociologist Enrique Gil Calvo has described the process perfectly: “From simple professional habit (the only news is bad news and bad prospects), the

press creates negative expectations rather than positive ones, with the only limits being the credibility of the forecast and the credulity of the audience. This is how the media, as they compete with one another in creating negative expectations, infect each other with the syndrome of alarmism, creating, as a result, a collective climate of opinion which promotes social panic. And in this way, as competition between the media intensifies, so an epidemic of alarmism is unleashed which is not social (transmitted from person to person) but media-based (transmitted from media organization to media organization), contributing to the eventual eruption of a social crisis.”<sup>28</sup>

## The crisis in the social perception of information

We have known for many years that surveys of social perceptions agree in identifying the high level of public interest in all issues related to medicine and health, while at the same time highlighting the relatively poor quality of the information received from the traditional media.<sup>29</sup>

An analysis in *Consumer* magazine in 2006 established that sport and politics account for about half of the output of news programmes; by contrast, less and less is dedicated to culture, the environment, science, health and consumer affairs. Only 2.1% of the news on the main news programmes on Spanish TV channels (public and private, state and regional) is dedicated to health; 2% to the environment and 1.1% to consumer affairs and daily life (issues which sometimes also relate to health).<sup>30</sup>

A more recent study by the Scientific Communication Observatory-UPF conducted in cooperation with the Consell de l'Audiovisual de Catalunya (CAC) found that Catalan TV allocates only a limited amount of space to information about science and technology. The format where this is clearest is in news programmes. The study found that the news apportions an average of 1.7% of total time to news about science and technology, the environment and health. General information, documentary and discussion programmes on Catalan channels (TV3, Canal 33, TVE-Catalunya, 8TV and BarcelonaTV)



were analysed with the aim of quantifying the coverage of these subjects, using three categories: science and technology, the environment and health. The result for these channels was that an average of 9% of their general programming was allocated to addressing scientific, medical, health and environmental issues, with Canal 33 apportioning the greatest amount of space, at 20%.

Of the different genres which made up the general programming dedicated to science and technology on Catalan TV, nature was the area to which most time was dedicated (34%). The behaviour, lives and characteristics of animal species, ecology and natural disasters were the most common topics in this area, addressed primarily in documentaries, cultural programmes and cartoons. Next was the weather (27%, consisting primarily of brief weather reports following the news), and third came medicine, biomedicine and quality of life (15%). This is a broad area which specifically includes common issues such as nutrition, sexuality, certain illnesses such as cancer, AIDS and heart disease, their treatment, and the health system. Some way behind are biomedicine (GM food, stem cells, genetics, cloning, assisted reproduction) and psychology and mental health (mental illness, alcohol and drug addiction, social relations). The area of medicine and quality of life is represented in a broad number of media formats, and is the subject of discussions as well as providing the context for TV series and films.<sup>31</sup>

We are unfortunately all too well accustomed, on the increasingly ubiquitous TV talk shows and radio discussions (with participants who show no hesitation in offering an opinion on every topic there is, often with little knowledge of the subject), to the mixing of scientific concepts with others (the majority) which are mere pseudoscientific speculation. These participants draw on their questionable position as experts and add to the stream of continuous cultural education claims whose consequence — we must insist — is to make the general public more ignorant, not better informed.

For their part, TV series often represent medical practice and related issues of bioethics in ways which are surprisingly realistic, yet sometimes inaccurate. These programmes affect the attitudes and knowledge of the general public and, in particular, of students of medicine and nursing, because they

Antoni Trilla

## Médicos: de la realidad a la TV

**M**arcus Welby, *Doctor en Medicina y Centro médico* (con el guapísimo doctor Gannon) (emitidas de 1969 a 1976) fueron las series médicas con las que viví mi etapa escolar y universitaria. Luego, *A cor obert* (*St. Elsewhere*, 1982-1988), mi serie favorita junto con la famosa *Urgencias* (*ER*, 1994-2009, incluyendo a George Clooney en su reparto), han sido las que han dado entrada a la plétora actual de series médicas, como *Anatomía de Grey*, *Scrubs* o *House*, norteamericanas, y *Hospital central*, española, entre otras.

¿Reflejan la realidad? La respuesta más prudente es: únicamente de modo aproximado y, en gran parte, distorsionada y condicionada por el formato televisivo.

A. TRILLA, médico del hospital Clínic y profesor de la Universitat de Barcelona

En las series de antes de 1990, una medicina y una televisión menos tecnificadas daban un ritmo más pausado, más personal, a los sucesos y problemas planteados. En las actuales, la velocidad y la tecnología aplicada, tanto a la medicina que aparentemente se practica en cada capítulo como al formato de la serie, son excesivas y no reflejan la realidad. No deben reflejarla: son series de ficción, no documentales.

Las relaciones entre los pacientes, el personal médico, de enfermería y de la administración son bastante más normales, menos dramáticas y más previsibles que en televisión: reflejan simplemente la pluralidad de nuestra sociedad. Los profesionales sanitarios somos personas dedicadas a nuestro trabajo, que intentamos hacer las cosas lo mejor posible, con recursos muy limitados y, eso sí, con salarios muy por debajo de los que cobran los afor-

tunados actores que representan nuestro papel en televisión. No somos para nada infalibles en nuestros diagnósticos, ni estamos dotados de la capacidad de operar o tratar médicamente cualquier cosa en cualquier momento, como nuestros colegas de ficción. Atendemos a una gran mayoría de pacientes cuyas enfermedades, que les suponen una gran preocupación personal y limitan su calidad de vida, no son nada raras ni espectaculares. Los diagnósticos de alta realismo más habituales son parto normal, insuficiencia cardíaca, enfermedad pulmonar crónica y colocación de prótesis de cadera. No tienen glamour.

La vida diaria en un hospital, aun ajetreteada e interesante, discurre de forma más previsible y ordenada. Sería bastante aburrido filmar esta realidad a su verdadero ritmo. La audiencia y el *share* se resentirían. No duraríamos ni dos episodios.●

constitute a highly realistic representation of medical practice and the associated ethical problems. An internet survey of medicine and nursing students, designed to identify viewing habits of the audiences of these sorts of programme, and the impressions they derived from them, found that over 80% of students view medical series. The impressions of students with hospital experience tend to be more negative than those who do not have such experience. They also found that viewing medical series was a social event, and that many students discussed the ethical problems shown in the series with their friends. These series could, then, stimulate students to think about and discuss such issues. The survey, conducted in 2008 by researchers at the Institute of Bioethics at Johns Hopkins University<sup>32</sup> found that 65% of nursing students and 76% of medicine students watch *House*. According to the same survey, published in the *American Journal of Bioethics*, students also took a particular interest in *Grey's Anatomy*, another series which often portrays doctors acting in a manner which is far from professional.

For the majority of followers of these series, particularly those who study medicine, it is very clear that series about doctors only bear a faint resemblance to real medical situations. However, the study authors asked wheth-

er mere exposure to these programmes (and the trivialized ethics they contain) could affect the attitudes of doctors and patients towards real medical practice.

One general consequence has been a gradual drift towards the sensationalization and trivialization of medical and health news, with the serious risk of disinformation which may be associated with this phenomenon which is an inherent part of today's mass media world. As a result, the existence of the specialist press (written with greater rigour by experts, and published both on paper and on the internet) and accessed by a more demanding readership, has become increasingly important.

Another consequence is that scientists, medical researchers and health managers have, in recent years, lost much of their social authority in the mass of indistinguishable information in which we are all immersed. They may be partly to blame, but this loss of scientific authority is also clearly attributable to a lack of political will, on the part both of national governments and of the executive of the European Union. Perhaps we should follow the example of institutions such as the FDA (Food and Drug Administration) or the EPA (Environmental Protection Agency) in the United States, which provide some degree of reassurance when dealing with issues deriving from scientific and medical practice and the diagnostic and therapeutic applications.

Politicians should encourage the creation of bodies whose independence and scientific expertise inspire trust among the general public, so that we can continue to address the growing challenges posed by the rapid introduction of new technologies and the competing interests which come together in a society increasingly dominated by the spiral of consumption. However, it appears that politicians are afraid of the existence of respected, independent sources, despite the fact that this lack harms politicians too, because the result is that political bodies lose credibility.

At the same time, the scientific world must seriously reflect upon its own loss of authority, something which could have dire consequences for its future given that a society which has lost trust in scientific authority is likely to be less willing to invest in science and less supportive of public funding for such

initiatives. There are signs that things are already moving in this direction, and it would be a grave error to make no move to check them.

Scientists and mediators of information — and not just politicians, as has long been the case — are in danger of sliding slowly towards a loss of credibility and authority. Perhaps we should consider together how best to react.

## The crisis in the access to knowledge

The change which is occurring in how the public accesses information and knowledge is profound and irreversible, and the media must adapt or die. There is a need for critical capacity in the media and among journalists in order to conserve the traditional values which made this sector a respected source of information, but also — and above all — we need to campaign for education to enable the public to chart its way through the stormy ocean of communication and information, battered as it is by new winds and tides.

The trend away from the mediation of scientific information could be very positive, enabling closer links between information sources and society. But it could also have a negative side, and what is at stake here is the regulatory role which should be fulfilled by journalism in its search for the truth and the greatest possible objectivity. It is, of course, worth asking whether the media have performed this role in the recent past or whether they are performing it today or whether, on the contrary, the way in which they operate and the interests behind them have contributed to a gradual loss of prestige and the alienation of their audience.

Should scientists and doctors also be communicators, or is it best for this task to be delegated in full to communications professionals: journalists, press office staff etc.? In the Declaration on Science and the Use of Scientific Knowledge, adopted at the World Conference on Science on 1999 under the auspices of UNESCO,<sup>33</sup> it was established that: a) scientific knowledge should be shared; b) there was a need for authentic cooperation between governments, civil society, the business sector and scientists, and c) scientists should be governed by the relevant ethical standards.



In the same way, in the United Kingdom, the Science and Technology Committee of the House of Lords in 2000 recommended direct dialogue with the public.<sup>34</sup> These recommendations were issued after a large part of British (and European) society had lost faith in the Government and in science after the “mad cows” scandal, which reached a media peak in 1996.

Jane Gregory and Steven Miller, in *Science in the Public: Communication, Culture, and Credibility*<sup>35</sup>, reflect on the importance of openly recognizing the motives which lead scientists to communicate with the public, and group them as follows: a) enthusiasm (the researcher is passionate about his or her area of work and wants to share it with others); b) improving the skills and knowledge of the audience; c) improving existing democratic processes or helping to create new ones where none exist; d) preventing the alienation of certain sectors of society, and e) serving the interests of the scientific community and the organizations which fund it.

We can also group classify the motives underpinning the public communication of science depending on who benefits:

- Each of the individuals who belongs to the society, because their knowledge of the world increases, as does their capacity to take informed decisions and to use the new applications developed by science in an effective manner.
- Society in general also benefits from the public dissemination of knowledge, especially if it has been generated as the result of public investment; it is an essential element of democracy and can contribute to a country's welfare and economic development.
- Science and culture in general: when knowledge is not restricted to the few but expands, it generates new research questions not just in the original field but in others as well, even leading in some cases to the creation of new disciplines (bioinformatics is an example).
- The scientific community: scientists are the first to benefit from greater public knowledge of science and scientific processes. Obscurity breeds fear, while transparency generates public trust. Furthermore, if one person does not communicate, there will always be somebody else

who does (and he or she will not always do so with the intentions and clarity one might wish for).

- Aesthetics: the public communication of science takes many forms, some of which are of extraordinary visual and artistic beauty. Examples can be found in books, photographs, pictures and illustrations, videos and documentaries.

## The internet: a strategic communication tool

The new media have a vital role to play in this educational task: social networks have become a new platform which enables more people to access good information via a cooperative system which brings together doctors, patients and the general public, bypassing the traditional media. In years to come, social computing could play an increasingly important role in building citizens' involvement in cultural, social and political debate, and in guaranteeing social cohesion and harmony, and it could provide a platform for a dialogue about major challenges, including that of communication. It enables users to become active participants, collaborating in the production of content, deciding on how this is rated, sharing storage capacity, increasing connectivity, producing collective knowledge, and generating and reinforcing networking effects. Social computing has the potential to transform work, health and education, while also enabling new models of horizontal collaboration in which users assume new roles in the creation of content and the provision of services. Social computing driven by innovation and cooperation is creating new resources which could be used by governments, politicians, civil society, intermediaries and citizens to work towards the achievement of public policy objectives in multiple areas, including direct and indirect access to health education through the new internet-based communication system.<sup>36</sup>

One need only note that in the United States 61% of internet users access information about health, making it one of the primary subjects of internet information searches. For the majority of users, the experience is far more

positive than negative,<sup>37</sup> and this increases with the possibility of exchanging information and experiences with other users offered by what has been termed *communication 2.0*, in which we can all be both producers and consumers of information. While this undoubtedly opens up a whole range of possibilities, we should also be mindful of the potential drawbacks. For example, how do we distinguish between truly valuable information and that which is misleading? Today, more than ever, it is essential that there is a solid knowledge culture if the new communication tools are to be genuinely useful for the population as a whole. We have moved from saying “I saw it on TV”, “I heard it on the radio”, “I read it in the paper” or “I found it on the internet” to the possibility of “I know because I learned it on my social network”. But for this we need a society which is sufficiently well educated and discriminating to be able to select accurate, useful information from the ocean which is today’s communication world.

The result is that patients ask doctors if information they have found on the internet while seeking to better understand their diagnosis is true. A study conducted by Spanish researchers reveals both the advantages and drawbacks of using the internet as a source of medical information. It found that 31% of doctors believe that the internet complicates their relationship with patients and undermines their credibility.

Health information on the internet is changing the relationship between doctors and patients. As José Joaquín Mira, researcher at the Miguel Hernández University and lead author of a study in the journal *Atención Primaria*,<sup>38</sup> explains, “although e-patients are a new phenomenon which is growing at an exponential rate, there are very few studies analysing them from the point of view of doctors.” For this reason, the researchers analysed the opinion of 660 doctors in the Spanish National Health System (330 in Primary Care and 330 in hospitals) in the provinces of Alicante, Madrid, Zaragoza and Huesca. The results revealed that 96% of doctors had been asked by their patients about information from the internet. Furthermore, almost three out of ten doctors recommended websites to their patients.

Hospital doctors spent more time on the internet, made more use of web resources in the training of house officers, and worked more with specific

websites than their colleagues in primary care. However, they had similar opinions regarding the influence of the internet on their patients. For 31% of doctors, the internet complicated their relationship and undermined their credibility. The main advantage of the internet for patients (42%) was identified as the fact that it helped them to understand their illness. However, only 20% of doctors interviewed believed that the internet increased patient autonomy.

“All specialists agreed that they do not believe the internet promotes patient autonomy. In addition, many felt that it could undermine the credibility of the doctor and when seeing patients they therefore often suggest websites to complement the information,” explained Mira.

“In Spain, it is estimated that slightly more than 40% of the population use the internet to search for information about health,” Mira says, going on to argue that although this is one of the areas where innovation is most intense and there are great prospects for the future, “it also gives rise to new questions, despite which it has been the subject of very few studies to date.”

A similar study was presented in April 2010 in France, conducted by the Group for the Study and Research of the Market in Health (GERMS) of the Pierre et Marie Curie University.<sup>39</sup> Patients attend consultations with pre-existing ideas about a possible diagnosis, almost requesting a specific treatment or prescription, and with a file about their possible illness which they have created on the basis of the interpretation of hypothetical symptoms they have found on the internet. In response, some doctors have taken the course of recommending specific health portals — in the knowledge that they are reliable — in order to help patients to find more information and to better understand and expand upon what they have been told by the doctor. Approximately one third of the 42 million internet users estimated to exist in France consult the internet for medical purposes. With the exceptions of users with sufficient prior knowledge, the majority use search engines to find information about specific illnesses, without considering the source of the information or its scientific credibility. Users rarely go straight to an accredited, reliable website. The typical user is a young woman who is concerned about a health problem in her life, either because it affects her directly or

## Avec Internet, le patient joue au médecin

Selon une étude, un tiers des internautes français recherchent des informations médicales

### Santé

Des patients qui arrivent avec « une idée de diagnostic, une quasi-conviction, voire un gros dossier apparentement constitué sur Internet ». Marie-Adèle Pré, médecin à Veneux-les-Sablons (Seine-et-Marne), a fini par s'y habituer. Si tous ne confient pas avoir consulté un site médical, elle le repère surtout au vocabulaire utilisé. L'intrusion d'Internet dans l'intimité de son cabinet ne l'agace pas pour autant. Elle s'en sert plutôt : « Il m'arrive de conseiller des sites dont j'ai vérifié la sérieux, et où je sais que mes patients pourront trouver les outils pour mieux comprendre ce que je leur ai dit », explique-t-elle.

Environ 800 sites français sur la santé sont aujourd'hui labellisés



because it affects a family member. While it is true that only 14% of those interviewed trust fully the information they find on the internet, it is also the case that a growing number of people pay more attention to the appearance and presentation of websites than to their content.

The health industry has already responded to this new communications challenge. Social networks have changed the way in which health providers and pharmaceutical companies communicate with the public. Today, consumers can follow health conferences in real time, search for information or share web links instantly. Facebook, Twitter, YouTube and other social networks already play an important role in any health communication plan.

Understanding the threats and opportunities which these social networks represent has become an essential part of the marketing strategies of health professionals. If you work in health communications and want to capture your audience's attention, increase business opportunities or improve your reputation, you have to follow the audience and adopt the social networking tools which best fit the objectives you used to achieve using traditional marketing activities.

The opportunities that social networks offer with regard to health communication are well known and include low cost, high impact, direct communication,

transparency and accessibility. However, there are also some risks which must be taken into account:

1. Legal and privacy considerations. Health information is a sensitive issue, and its use and disclosure are regulated in many countries. Many hospitals and pharmaceutical companies are wary of using social networks precisely for reasons of privacy and confidentiality. To minimize these concerns, some social networks have added configurable privacy options which allow users to control who can view their profile or personal data.
2. Reputational risk. A logical concern for health professionals or pharmaceutical companies is that the content generated by users may pose a threat to the reputation of the company. You must bear in mind that dialogue will take place with or without your participation, and in the event of crisis social networks may provide you with the opportunity to provide a fast and comprehensive explanation of your point of view, and to interact immediately with all those involved.

The internet provides access to an abundant source of scientific and particularly medical information, as occurs in many other areas. This information can clearly help people to reach a better understanding of both health and illness. However, it also has the potential to increase the anxiety felt by those with little or no medical education, particularly when the internet is used to reach a diagnosis on the basis of assumed symptoms. This combination of excess information, on the one hand, together with insufficient skills for managing it, on the other, may not only generate additional anxiety but can even lead to the phenomenon of *cyberchondria*, a term coined by the researchers Ryen White and Eric Horvitz of *Microsoft Research*<sup>40</sup> to describe “the unfounded escalation of concerns about common symptomatology, based on the review of search results and literature on the Web”. This can culminate in a new type of anxiety. White and Horvitz conducted an extensive study of the experience of how people search for medical information online, often in response to common symptoms which are usually benign, such as headache, but which can incorrectly be interpreted as very serious: for example, as indicative of a brain tumour. Their results reveal that search



engines have the potential to provoke an unnecessary escalation of medical information which goes far beyond what was initially sought. This escalation is influenced by the quantity and distribution of the medical information to which users have access: the inclusion of particular terminology on the pages visited may lead to the exaggeration of symptoms, and the user may be predisposed to exaggerate the seriousness his or her condition in the face of more reasonable explanations of potential complaints, where these exist.

It is clear that in an area as sensitive as the interpretation of health there are only two ways of palliating these negative effects: improving information sources (given that control is impossible) and, above all, better education of the general public in health issues so that people are more able to make judgments about the information available. At the same time, we must always remember that, however much information we have, this can never replace a relationship of trust between doctor and patient.

## More is not always better

Gary Schwitzer, Professor at the University of Minnesota (USA) and editor of the electronic journal *healthnewsreview.org*, argues that “the education of the healthcare consumer is so important and it is so much in jeopardy; consumers are flooded by information and they don’t always have the ability to judge the veracity, the truthfulness of the information or the integrity of the source... Both science and journalism must help develop and nurture healthy scepticism in the public... Healthy sceptics who learned a few simple but vital lessons: that in healthcare more isn’t always better; newer isn’t always better; and beware of anyone who claims that it is.”

*Healthnewsreview.org* is a portal which analyses medical and health news and evaluates the content applying the ten criteria below:

- Did the story adequately discuss the cost?
- Did the story avoid disease-mongering? (Exaggerating the seriousness of a condition or writing about a normal health variation as if it were

a disease: for example, baldness, wrinkles, pregnancy, menopause, toenail fungus.)

- Did the story evaluate the quality of the evidence? (Not all studies are equal.)
- Did the story quantify the potential benefits? (We expect the story to do so in absolute statistical terms, not just relative risk-reduction terms.)
- Did the story quantify the potential harms? (Giving the size or the scope of how large the potential harm might be.)
- Did the story establish the true novelty of the idea? (Is this really news, or is this old fish wrapped in new newspaper?)

- Did the story establish the availability of the approach? (Or is it really talking about something which is in the early stage of a trial and may not be available for years?)
- Did the story use independent sources and did the reporter identify potential conflicts of interest?
- Did the story compare the new idea with existing options?
- Did the story appear to rely on a news release from some vested interest?

Gary Schwitzer argues that “many newspaper articles read like advertising rather than news.”<sup>41</sup> “The industry — including drug makers and device manufacturers, hospitals and medical centres — know that the news industry is hurting financially, and take full advantage of the weakness of their colleagues by flooding them with news releases and marketing material. With staff cutbacks, there is a tendency to use unfiltered publicity material from a

**LifeExtension™**

MEMBERSHIP | PRODUCTS | MAGAZINE | HEALTH CONCERNS | NEWS | ABOUT US

LOGIN | PROFILE | FAVORITES | ORDER HISTORY | VIEW CART | CHECKOUT

**Resveratrol Caps**  
60 capsules  
Item Catalog Number: 655

Findings from published scientific literature indicates that resveratrol may be the most effective plant extract for maintaining optimal health.<sup>106\*</sup>

Red wine contains resveratrol, but the quantity varies depending on where the grapes are grown, the time of harvest, and other factors. After years of relentless research, a standardized resveratrol extract is now available as a dietary supplement. This whole grape extract contains a spectrum of polyphenols that are naturally contained in red wine such as proanthocyanidins, anthocyanins, flavonoids, etc.

The resveratrol used in these products is extracted from organic grapes and is in a natural matrix that includes many other polyphenols.

References

**Supplement Facts**

**Resveratrol Caps**

units: ☐ Members ☐ Non-members

|   |              |              |
|---|--------------|--------------|
| 1 | \$24.00      | \$32.00      |
| 4 | \$22.13 each | \$29.50 each |

add to favorites | add to cart

Abstracts | Protocols | Articles



El nuevo suplemento  
de bienestar de  
**LA VANGUARDIA**



**SALUD&VIDA**

Sueño placentero  
Como dormirte el  
descanso de tu bebé

Fitocosmética  
Cuidarse con productos  
vegetales naturales

**Adicción al trabajo**  
Cuando la actividad laboral se convierte en una obsesión

vested interest. It is ironic that in some newsrooms there are journalists working on important, difficult investigative stories, while across the newsroom there are other people who are producing soft, fluffy, one-sided, simplistic, unquestioning stories that don't dig one centimetre beneath the surface.

“Add to that the fact that the amount of money being spent by drug companies on direct to consumer drug advertising more than tripled between 1997 and 2005 in the United States,

growing from 1.3 billion dollars to 4.2 billion dollars since restrictions governing drug ads were relaxed by the US Food and Drug Administration. Every day in America, newspapers, websites, television and radio churn out new stories for us about new stuff in healthcare: new drugs, new devices, new scanning machines, new dietary approaches, new surgical procedures. Every night on prime time television, direct to consumer drug ads (which are only allowed in the US and in New Zealand) paint pretty pictures of sad people getting happier, or achy people becoming pain-free, or the green toenail fungus monster being conquered, or suddenly sexually fulfilled couples sitting in bathtubs on a hillside. Many of the claims for all of this new healthcare stuff are, to be kind, simply too good to be true.

“It’s like a powerful firehose flooding consumers every day, when all they want and need is a tiny sip of useful healthcare information to help them navigate the very complex US healthcare system (or lack of a system). Trying to get a drink from a firehose is both pointless and dangerous. Many news organizations live and die by what is published in medical journals each week. But that is a biased view of progress in medical research. It is well known that there is a publication bias in favour of positive findings; so is the practice of drug companies to squelch negative findings so that they are never submitted for publication; so is the practice of what we call ghost-writing, whereby drug companies have gone to great lengths to turn scientific articles into marketing vehicles for their products.”

At the same time we have to bear in mind that the timescale for scientific research and the news timescale are frequently incompatible. What is the life cycle for a new and important clinical discovery from publication of the first article in a scientific journal until it actually reaches the hospital or a pharmacy? By monitoring medical treatments published in the scientific literature, an analysis team at the Institute for Clinical Research and Health Policy Studies at Tufts Medical Center (United States) has reached the conclusion that it takes an average of 24 years from the first mention of a new discovery until it becomes an effective therapeutic intervention.<sup>42</sup> This statistic is derived from analysis of “101 very promising announcements with clear clinical potential” published between 1979 and 1983. None became a

truly extensive treatment before 2003 and, what is more, 96 never became a reality.

This study empirically demonstrates the lengthy period which elapses between a given discovery and its translation into an effective application. This characteristic makes clear the immense challenge faced by the scientific world in justifying funding and the time which must be invested to achieve tangible results and, above all, how complicated it is to transmit to the public the process which leads to a scientific discovery... Without forgetting one crucial issue: how to avoid creating premature expectations which may damage science’s public credibility.

We need to ask whether the continuous cascade of scientific information about innovations which are the product of very preliminary if promising experiments is beneficial or counterproductive for science itself. The discovery of the gene for an incurable disease, the discovery of a molecule which may one day be used to cure a particular kind of cancer, preliminary experiments on a potential vaccine against a pandemic in the developing world, and all of the other stories we are so used to hearing in the media: are these really useful as news stories which contribute to the education of the general public or are they merely just one more anecdote among the many which fill news programmes and newspaper pages, day after day, and whose real function is that of entertainment?

There is no question, however, that it is also important that the public should understand that converting laboratory ideas into clinical applications is a costly process both in terms of time and money; and, more importantly, that it is worth the effort. Without this process, our life expectancy would not have increased in the way that it has over the last century. Basic research requires time, and science cannot advance without it and without the inevitable blind alleys this includes. For this reason, the information which affects society should be contextualized properly and the public should be capable of understanding what scientific methodology entails, from hypothesis to thesis passing through the indispensable processes of experimentation and demonstration. This is the dilemma for good scientific and medical information. Is the mass media doing this?



Regardless of whether the answer is yes or no, one thing is very clear: scientific innovation must coexist with standards and regulations on the introduction of the new technologies that society would like to grant democratically. This is a debate which we cannot avoid holding, and the media must contribute to it. Once this basis has been established, information and above all the creation of a well-educated society capable of exercising critical judgement are at least as important as the capacity to innovate. Public opinion is essential to the successful completion and application of any technical, scientific or medical innovation. The only way of combating mystification is through education, culture and scientific knowledge. And this requires high-quality scientific and medical communication.

## Communicating in a climate of trust

It is some years now since the Scientific Communication Observatory at the Pompeu Fabra University began the task of reflecting upon how to improve the process of communicating scientific and medical knowledge to society through the mass media.

In 2001 we wrote, “We can imagine the quantity of messages being directed at society through the media which generate expectations, create confusion or simply entertain us... but which have a major impact on a public which is highly sensitive to anything concerning health and personal welfare. We are facing a serious problem in how we transmit scientific culture to society, and I would argue that not everything which is published in reputable scientific journals should also be reproduced in the mass media. All of this causes us to reflect upon the need of all those who form part of this knowledge transmission chain — scientific journals, scientists, journalists and editors alike — to establish an ethical code when publishing medical and health news for society, and to ensure that this ethics of medical communication is applied at all levels.”<sup>43</sup>

This notion was echoed by philosopher and anthropologist Georges Kutukdjian when he argued that, “Article 13 of the Universal Declaration on

the Human Genome and Human Rights” is absolutely essential. It refers to the responsibility, on the one hand, of researchers and, on the other, of those with the job of drawing up scientific and medical policies. These two parties have specific, individual responsibilities for accuracy, care, intellectual honesty and integrity when conducting research. Society in general has had great difficulty understanding and accepting this. In my opinion, the responsibility for this lies with scientific journalists and communicators: they must seek to make people understand that science is not based on a single, absolute truth [...] Scientists should be aware that they are responsible for communicating the results of their research to the public, and that to this end they need to develop their communication skills. For example, doctors use communication strategies as part of the relationship with patients. In the media, it would be good if there were more scientific programmes or supplements, so long as these incorporated an ethical approach to the issues under discussion. In this respect, the media could perform the role of mediators or advocates when considering controversial issues. Finally, we need to expand public debate of this issue by civil society. One example of this is by organizing opportunities for discussion which bring together doctors, philosophers and legal experts: where a journalist with experience of public debate could perform the role of moderator. This is, unquestionably, a way of strengthening the democratic process in society”<sup>44</sup>

One expression of the need for this debate was the seminar organized in 2001 by the Víctor Grífols i Lucas Foundation on “The ethics of medical communication”, the proceedings of which were published as a monograph<sup>45</sup>. This debate has continued and expanded in the ensuing decade, primarily as a consequence of the massive and indiscriminate dissemination of scientific and medical knowledge via the internet. Today more than ever it is essential to improve this dichotomy of transmission and perception which has such an influence on public health culture and education. Since then, many other

\*\* The Universal Declaration on the Human Genome and Human Rights was adopted by UNESCO on the 50th anniversary of the Universal Declaration of Human Rights on 10 December, 1948. Available at: [http://portal.unesco.org/en/ev.php-URL\\_ID=13177&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html)

voices have been raised, calling for rigour and responsibility in a sphere where ethics must be the essence of communication.

“Scientific communication in medicine and health faces new challenges which may threaten its credibility and its very nature. The first of these is the pressure on medical news to compete with other headlines which are generally more frivolous. The second concerns its devaluation as a source of high-quality scientific information. And, finally, there is the constant pressure to transform it into a vehicle of commercial or institutional publicity, at the services of interests which obstruct a critical comprehension of science,” argues Miguel Moreno, holder of a Ph.D. in Philosophy, and a Master in Bioethics from the University of Las Palmas and a specialist in the Social Communication of the Medical and Health Sciences. “Detailed, critical analysis of scientific activity, designed for a mature, intelligent readership which seeks to improve its understanding of science is an ineluctable professional responsibility of the scientific journalist. Their mission is not just to publish surprising results which grab the attention of jaded or uninterested readers, but rather to question and explain all the elements involved in the scientific undertaking (funding, conflict of interests, the criteria applied in science and technology policies, level of commitment in supporting research, etc.). The insatiable appetite for content cannot justify the trend to present trivial information as news by breaking it down and repackaging it for an audience assumed to be ignorant and uninterested in scientific matters. High-quality scientific journalism cannot exist without constantly striving to achieve critical insight into its subject and by contextualizing the results of research and the conditions which surround it, whatever the institutions or individuals involved. This includes aspects of the dynamics of science which are not usually treated as news but which are part of the wider human effort to understand and discover our world.”<sup>46</sup>

The *Comité Consultatif National d'Étique pour les Sciences de la Vie et de la Santé* (CCNE), an advisory body created by the French government in February 1983, issued a resolution in March 2010 on the *Communication d'informations scientifiques et médicales et société: enjeux éthiques*.<sup>47</sup> After analysing science, communication and current social trends — with particu-

lar emphasis on the impact of the electronic revolution — and highlighting the specific nature of the transmission and consumption of scientific and medical news, the CCNE issued a number of recommendations, including the following:

- Making the public aware of the critical importance of evaluating scientific information. It is essential that the public be sure that the information they receive from the media has been validated; and who better than scientists themselves to perform this task? The public also need to be informed of an important fact: the notion that validation can be revised and modified in the light of new scientific data.
- Encourage and urge scientists to communicate well and to become involved in validating and transmitting scientific communication to society. Require honesty and intellectual rigour when presenting results to the general public, particularly when there are financial implications in the search for public funds. Ensure that scientific developments are not released prematurely.
- Promote any initiative aimed to improve the general level of scientific education. Encourage general interest in the sciences. Favour early teaching of the sciences. Promote understanding of scientific methods and the history of science. Encourage scientific research bodies and institutions to be accessible to the general public. And increase the amount of scientific programming on radio and TV.

The CCNE hopes that by respecting everyone's freedom — scientific freedom, the freedom of the press, individual freedom — the communication of scientific and medical news to society may be accomplished in a climate of trust between science and society, and between scientists and the media. The CCNE stresses the importance of this in the struggle to create a better society in the future.

As Bertrand Russell said, “Democracy, though necessary, is not sufficient.” If we are to construct a coherent knowledge society, we need a science which is competent and honest, media which are transparent and balanced, and a public which is sufficiently well educated to be able to apply critical criteria to information. Ethics is the essence — and must be the catalyst — of this process.

## References

1. Kutukdjian, G. "Science and social responsibility: the ethical implications of scientific progress concern everyone", *UNESCO Courier*, May 1998. Available at: [http://www.accessmylibrary.com/coms2/summary\\_0286-9317716\\_ITM](http://www.accessmylibrary.com/coms2/summary_0286-9317716_ITM) and at: [http://findarticles.com/p/articles/mi\\_m1310/is\\_1998\\_May/ai\\_20825350/?tag=content;coll](http://findarticles.com/p/articles/mi_m1310/is_1998_May/ai_20825350/?tag=content;coll)
2. Revuelta, G., and De Semir, V. *Medicina y Salud en la prensa diaria — Informe Quiral 10 años, Observatori de la Comunicació Científica — Universitat Pompeu Fabra*, 2008. Available at: [http://www.upf.edu/pcsta-cademy/\\_docs/Quiral10.pdf](http://www.upf.edu/pcsta-cademy/_docs/Quiral10.pdf)
3. Camps, V. "Los medios de comunicación tienen responsabilidades en tareas educativas", *Comunicar*, 32, 2009, pp. 139-45.
4. NatureNews – Specials: To mark the 6th World Conference of Science Journalists from 30 June-2 July 2009 in London, Nature is shining a spotlight on the profession in changing times. Science journalism faces an uncertain future. But to what extent should scientists help – or care? Available at: <http://www.nature.com/nature/journal/v459/n7250/index.html>
5. *Newspaper Publishers Must Do More to Empower Brand Stewards*, Gartner Inc., (March 2009). Available at: [http://www.gartner.com/DisplayDocument?ref=g\\_search&id=911415&subref=simplesearch](http://www.gartner.com/DisplayDocument?ref=g_search&id=911415&subref=simplesearch)
6. Brainard, C. "CNN Cuts Entire Science, Tech Team", *Columbia Journalism Review*, 2008. Available at: [http://www.cjr.org/the\\_observatory/cnn\\_cuts\\_entire\\_science\\_tech\\_t.php](http://www.cjr.org/the_observatory/cnn_cuts_entire_science_tech_t.php)
7. Revkin, A. "Science Journalism Implosion, CNN and Beyond", *The New York Times*, 2008. Available at: <http://dotearth.blogs.nytimes.com/2008/12/04/science-coverage-imploding-at-cnn-beyond/>
8. Henry, N. "The decline of news", *SFGate.com*, 2007. Available at: [http://articles.sfgate.com/2007-05-29/opinion/17244065\\_1\\_chronicle-online-advertising-journalists](http://articles.sfgate.com/2007-05-29/opinion/17244065_1_chronicle-online-advertising-journalists)
9. Mooney, C. and Kirszenbaum, S. *Unscientific America: How Scientific Illiteracy Threatens our Future*, New York: Basic Books, 2009.
10. *Who is Futurity?* Duke University, Stanford University, and the University of Rochester lead a consortium of participating universities that manages and funds the project. All partners are members of the Association of American Universities (AAU) or of the Russell Group. These organizations include the leading research universities in the United States, Canada and the United Kingdom. Futurity aggregates the very best research news. The content is produced by the partner universities, and submitted to *Futurity's editor, Jenny Leonard* ([editor@futurity.org](mailto:editor@futurity.org)), for consideration. The site, which is hosted at the University of Rochester, covers news in the environment, health, science, society and other areas. Available at: <http://futurity.org/>
11. *Direct to Consumer Science*. Science departments at newspapers everywhere are shrinking. One outlet that aims to help fill the coverage gap is Futurity.org, a new website that lets scientists publish their findings directly to the public. Michael Schoenfeld, *Futurity's co-founder, explains the site's mission in an interview in On the Air (NPR)*, 9 October, 2009. Available at: <http://www.onthemedias.org/transcripts/2009/10/09/04>
12. Wilkie, T. "Sources in science: who can we trust?", *Lancet*, 347, 1996, pp. 1308-11.
13. De Semir, V.; Ribas, C., and Revuelta, G. "Press Releases of Science Journal Articles and Subsequent Newspaper Stories on the Same Topic". *JAMA*, 280, 1998, pp. 294-5. Available at: <http://jama.ama-assn.org/cgi/reprint/280/3/294>
14. Woloshin, S.; and Schwartz, L. M. "Press Releases: Translating Research into News", *JAMA*, 287 (21), pp. 2856-8. Available at: <http://jama.ama-assn.org/cgi/content/full/287/21/2856>
15. Revuelta, G. Interview with Lawrence Altman: "Los press releases fomentan el periodismo perezoso y la información homogénea", *Quark*, 9, 1997, pp. 75-7.



16. Bosman, J. "Reporters Find Science Journals Harder to Trust, but Not Easy to Verify", *The New York Times*, 13 February, 2006. Available at: <http://www.nytimes.com/2006/02/13/business/media/13journal.html> and at [http://www.woodymatters.com/06\\_updates/NYTScience.pdf](http://www.woodymatters.com/06_updates/NYTScience.pdf)
17. Smith, R. "The trouble with medical journals", *Journal of The Royal Society of Medicine*, 99, 2006, pp. 115-9. Available at: [http://www.upf.edu/pcstacademy/\\_docs/200603\\_trouble.pdf](http://www.upf.edu/pcstacademy/_docs/200603_trouble.pdf)
18. Kiernan, V. *Embargoed Science*, University of Illinois Press, Urbana and Chicago, 2006. Interview with Vincent Kiernan about *Embargoed Science in On the Air* (NPR), 29 September, 2006. Available at: [http://www.onthemedial.org/transcripts/2006/09/29/05\\_Embargoed\\_Science\\_at\\_Google\\_Books](http://www.onthemedial.org/transcripts/2006/09/29/05_Embargoed_Science_at_Google_Books): [http://books.google.com/books?id=TLHGLtwbazAC&printsec=frontcover&hl=es&cd=1&source=gbs\\_ViewAPI#v=onepage&q&f=false](http://books.google.com/books?id=TLHGLtwbazAC&printsec=frontcover&hl=es&cd=1&source=gbs_ViewAPI#v=onepage&q&f=false)
19. Horton, R. "Science and the Media: Breaking the Embargo", *Science*, 315, 2007, pp. 331-2. Available at: <http://www.sciencemag.org/cgi/content/summary/315/5810/331>
20. Embargoes broken? *In the Field (the Nature reporters' blog from conferences and events, 2009)*. Available at: [http://blogs.nature.com/news/blog/2009/07/embargoes\\_broken.html](http://blogs.nature.com/news/blog/2009/07/embargoes_broken.html)
21. Hinnant, A., and Len-Rios, M. "Tacit Understandings of Health Literacy", *Science Communication*, 31, 2009, pp. 84-115. Available at: [http://www.allacademic.com//meta/p\\_mla\\_apa\\_research\\_citation/2/7/2/0/6/pages272061/p272061-1.php](http://www.allacademic.com//meta/p_mla_apa_research_citation/2/7/2/0/6/pages272061/p272061-1.php)
22. Schwitzer, G. "How Do US Journalists Cover Treatments, Tests, Products, and Procedures? An Evaluation of 500 Stories", *Plos Medicine*, 2008. Available at: <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0050095>
23. *Newsweek*, 13 March, 2006.
24. The magazine of the School of Journalism at Columbia University (USA) has discussed this issue: *Columbia Journalism Review*, March-April, 2006. Available at: [http://www.cjr.org/behind\\_the\\_news/newsweek\\_launches\\_savage\\_attac.php?page=all&print=true](http://www.cjr.org/behind_the_news/newsweek_launches_savage_attac.php?page=all&print=true)
25. *El Periódico*, 30 April, 2009.
26. *Le Monde*, 9 September, 2009.
27. *Médiatiques*, no. 45, 2009. Available at: <http://www.comu.ucl.ac.be/ORM/Mediatiques/Mediatiques45.pdf>
28. Gil Calvo, E. *Crisis crónica*, Alianza Editorial, 2009, pp. 88-9.
29. See surveys: National Science Foundation (United States, 2010). Available at: <http://www.nsf.gov/statistics/seind10/c7/c7h.htm>. Eurobarometer (Europe, 2007). Available at: [http://ec.europa.eu/public\\_opinion/archives/ebs/ebs\\_282\\_en.pdf](http://ec.europa.eu/public_opinion/archives/ebs/ebs_282_en.pdf). Fecyt (Spain, 2008). Available at: <http://www.fecyt.es/fecyt/docs/tmp/1113600113.pdf>
30. Analysis of TV news, *Consumer* (April 2006). Available at: [http://www.upf.edu/pcstacademy/\\_docs/TVConsumer2006.pdf](http://www.upf.edu/pcstacademy/_docs/TVConsumer2006.pdf)
31. Revuelta, G., and Mazzonetto, M. "La ciència i la tecnologia a la televisió d'àmbit català", *Quaderns del Consell de l'Audiovisual de Catalunya*, 30, 2008, pp. 69-80. Available at: <http://www.cac.cat/web/recerca/quaderns/hemeroteca/detall.jsp?NDg%3D&MQ%3D%3D&Jyc%3D&MzI%3D>
32. Czarny, M.; Faden, R.; Nolan, M.; Bodensiek, E., and Sugarman, J. "Medical and Nursing Students' Television Viewing Habits: Potential Implications for Bioethics", *The American Journal of Bioethics* 8, 2008, pp. 1-8. Available at: <http://www.informaworld.com/smpp/content~db=all?content=10.1080/15265160802559153>
33. Declaration on Science and the Use of Scientific Knowledge. Available at: [http://www.unesco.org/science/wcs/eng/declaration\\_e.htm](http://www.unesco.org/science/wcs/eng/declaration_e.htm). World Conference on Science "Science for the Twenty-First Century" Budapest (Hungary), 26 June - 1 July 1999.
34. Science and Technology, Third Report. *House of Lords, United Kingdom, February 2000*. Available at: <http://www.publications.parliament.uk/pa/ld199900/ldselect/ldsctech/38/3801.htm>

35. Gregory J., and Miller S. *Science in Public*. New York: Plenum Press, 1998.
36. The Impact of Social Computing on the EU Information Society and Economy – *Institute for Prospective Technological Studies*, 2009. Available at: <http://ftp.jrc.es/EURdoc/JRC54327.pdf>
37. The Social Life of Health Information. *Pew Internet and American Life Project*, 2009. Available at: [http://www.pewinternet.org/~media/Files/Reports/2009/PIP\\_Health\\_2009.pdf](http://www.pewinternet.org/~media/Files/Reports/2009/PIP_Health_2009.pdf)
38. Mira Solves, J. J.; Llinás, G.; Lorenzo, S., and Aibar, C. “Uso de Internet por médicos de primaria y hospitales y percepción de cómo influye en su relación con los pacientes”, *Atención Primaria*, 41, 2009, pp. 308–14.
39. “Avec Internet, le patient joue au médecin”, *Le Monde*, 14 April, 2010, page 22. Available at: [http://abonnes.lemonde.fr/aujourd-hui/article/2010/04/13/avec-internet-le-patient-joue-au-medecin\\_1332939\\_3238.html](http://abonnes.lemonde.fr/aujourd-hui/article/2010/04/13/avec-internet-le-patient-joue-au-medecin_1332939_3238.html)
40. White, R., and Horvitz, E. “Cyberchondria: Studies of the Escalation of Medical Concerns in Web Search”, *Microsoft Research*, November 2008. Available at: <http://research.microsoft.com/apps/pubs/default.aspx?id=76529>
41. Extract from paper by Gary Schwitzer at Campus de la Comunicación – UPF de Barcelona, at the *Jornada Comunicación en Salud 2.0*, 26 October, 2009, organized by the Scientific Communication Observatory – Pompeu Fabra University. Available at: <http://www.youtube.com/watch?v=raO6lriJQbI>, [http://www.idec.upf.edu/documents/091026\\_jmcc.pdf](http://www.idec.upf.edu/documents/091026_jmcc.pdf) and at: <http://www.escrituraprofesional.com/blog/la-salud-20-necesita-vitaminas>
42. Contopoulos-Ioannidis, D. *et al.* “Life Cycle of Translational Research for Medical Interventions”, *Science* 321, 2008, pp. 1298–9. Available at: <http://www.sciencemag.org/cgi/content/full/sci;321/5894/1298/DC1>
43. De Semir, V. “Noticia médica: ¿impacto científico o impacto mediático?”, *Quark*, 20, 2001. Available at: <http://www.prbb.org/quark/20/>
44. Kutukdjian, G. “El papel de la ética en la comunicación científica”, *Quark*, 20, 2001. Available at: <http://www.prbb.org/quark/20/>
45. “Ethics of medical communication”, *Monographs of Víctor Grífols i Lucas Foundation*, no. 6, 2002. Available at: [http://www.fundaciogrifols.org/portal/en/2/7353/ctnt/dD10/\\_/\\_/5ul/06-Ethics-of-medical-communications.html](http://www.fundaciogrifols.org/portal/en/2/7353/ctnt/dD10/_/_/5ul/06-Ethics-of-medical-communications.html)
46. Moreno, M. “Ética y comunicación social en biomedicina”, Instituto Roche, 2010. Available at: [http://instituto-roche.com/Legal\\_etica\\_y\\_comunicacion\\_social/V12.html](http://instituto-roche.com/Legal_etica_y_comunicacion_social/V12.html)
47. Communication d’informations scientifiques et médicales, et société : enjeux éthiques – CCNE, 2010. Available at: [http://www.ccne-ethique.fr/upload/CCNE-Avis\\_109.pdf](http://www.ccne-ethique.fr/upload/CCNE-Avis_109.pdf)

[Note: all online documents consulted on 15 March, 2011.]

**Debate and expert  
contributions**



The debate section of the seminar on Ethics: the essence of scientific and medical communication was chaired by Gemma Revuelta, assistant director of the Scientific Communication Observatory, with participants dividing into four working groups. Each discussion topic was related to the content of the paper:

- Health information and the crisis of the media.
- Citizen journalism and unmediated information.
- The boom in institutional communication.
- The dictatorship of the scientific journals and open access to knowledge.

The results and conclusions are set out below, many of which open up new channels for future research.

### WORKING GROUP CONTRIBUTIONS

## Health information and the crisis of the media

*Magda Bandera, journalist with "Público"*

*Victoria Camps, president of the Víctor Grífols i Lucas Foundation*

*Maria Casado, director of the Bioethics and Law Observatory at the University of Barcelona (spokesperson)*

*Gonzalo Casino, health correspondent for "El País" (spokesperson)*

*Marta Ciercoles, health correspondent for "Avui"*

*Miquel À. Mayer, director of the Medical Website of the Official College of Doctors of Barcelona (COMB)*

The economic crisis has revealed the crisis which has affected the media and the template for the practice of journalism for many years now. These models have been overwhelmed by a number of factors. Journalists are not up to what society expects of them; they are expected to filter all the many interests involved in a health sector which has been subject to gradual commercializa-

tion over recent decades (for example, the phenomenon of the medicalization of life). All of this has gone almost unnoticed by journalists.

We find ourselves facing a situation of rapid change. The traditional media are gradually shrinking. In the United States long-established newspapers are closing because their two main income sources — advertising and sales — have declined. In addition, alternative means of funding the press — for example, through the sale of collectible items, crockery, films etc. — has reached saturation point.

Those newspapers which have not closed have begun to get rid of science and biomedicine sections, deeming them surplus to requirements. It is important here to distinguish between science information and health information, because both their content and the economic interests behind them differ. Science reporting has proved more vulnerable to cuts than health reporting, because the latter is backed by advertising which has meant it has declined less dramatically.

An important point to consider is the objective being pursued with the information. The interests of those producing the information, those transmitting it, and those receiving it, differ widely. This conflict of interests should be discussed openly. Although health issues affect everyone, not everyone is interested in them. This raises the issue of whether all media should offer the same type of information: perhaps it would be better if the television concentrated on more immediate information, while the written press offered in-depth coverage.

## Limitations and problems of journalism

- There is a notion that journalists do not investigate. They receive information from press agencies or leading scientific journals and use it unquestioningly. One of the ethical duties of journalism should be to clearly explain the source of any information and its credibility.
- Another important ethical issue concerns the lack of follow-up of news items. It is sad to see how news items simply disappear after a certain period of time, generating false expectations. We never read of

how an innovation has failed, of how an illness is incurable, or of how a newly discovered 'treatment' is still experimental.

- Journalists are the final stage in the information production process, the most vulnerable, and the element with the least room for manoeuvre. Many institutions wish to gain visibility; and to achieve this they dedicate considerable resources to the production of press releases and to actions designed to influence journalists (from trips to training courses). It is easy to see how journalists have been used to provide a conduit for certain pieces of information. Clear examples of the above include Viagra, where the ground was prepared by talking about erectile dysfunction before the treatment was presented, or super aspirins, which were the focus of extensive media attention before clinical trials showed that the adverse effects outweighed any benefits. Journalists find that their agendas have been taken over or distorted by others. It is hard to conceive just how far news presentation is imposed by external factors. For example, the *British Medical Journal* comes out on a Friday, and the media therefore feels obliged to report on the innovations covered in it.
- The media continue referring to each other, with the result that they all publish the same news. It has been argued that there is a degree of complicity between journalists, journals and even researchers, to ensure that issues selected by certain interests receive more attention.
- The lack of training for scientific journalists is another problem faced by the profession. How far are journalists prepared to help readers become discerning consumers of health news? How can they know whether an item deserves to be treated as news? Journalists are not trained in biomedicine. This is the only field where they cannot address the source on a level playing field, but have instead to play the role of the layperson who receives scientific information but is not in a position to disagree with the source as we would normally expect.
- The dictatorship of the image and of design dominates the current situation. Sometimes news is dictated by a photo which then provides the basis for a report. However, it is also true that there is a big differ-

ence between newspapers and television, and that Spain has a tradition of quality newspapers, even if this is gradually declining. Perhaps this is one of the greatest mistakes of quality journalism: the belief that by reducing its quality a newspaper will increase its readership, when the most likely outcome is that it will lose the few readers it has left. Curiously enough, this situation is universal and is now affecting the major newspapers in Spain.

## Citizen journalism and unmediated information

*Cristina Aced, communication consultant and contributor to the Scientific Communication Observatory of the Pompeu Fabra University*

*Laura Chaparro, student on the Master's Degree in Scientific Communication at the Pompeu Fabra University*

*Francisco Lupiáñez, researcher at the Institute for Prospective Technological Studies (IPTS)*

*Josep M.ª Martí, dean of the College of Journalists of Catalonia (spokesperson)*

*Teresa Sánchez, student on the Master's Degree in Scientific Communication at the Pompeu Fabra University*

We always look at things from the point of view of the media, not of the audience. This time, we've tried to look at what is happening on the internet from the perspective of the 'audience'. The internet has given rise to the phenomenon of citizen journalism and unmediated information. We have the feeling that the appearance of the internet has put a question mark against the conventional pact which existed between the media and audiences. According to this agreement, the media were institutions which were accredited to inform: they were identifiable companies and as a result members of the public had certain rights they could exercise in the event that they felt they had been prejudiced by the information transmitted.

The internet questions this understanding because there is a social perception that the media have not done their job properly, particularly with regard to participation and interactivity, a feature of the internet which the traditional media lack. The result is that anyone with access to the internet can become a journalist and disseminate information, reducing the significance of traditional media.

Citizens' access to the media was relative: everything was done for them, but without involving them. In the 1930s, the playwright Bertolt Brecht — who was also a theorist of the radio — argued that this could go from being a great distribution device to being a great communication device. He understood communication as a two-way process, but this conception never took root.

Now, just as citizens are assuming an active role and playing an active part in the process of creating and transmitting information, a number of issues arise.

Of course, if we adopt a defensive attitude, we could argue that much of the information on the internet has not been checked or documented; we do not know where it comes from, but it is clear that unmediated information is becoming increasingly widespread and the conventional media often end up echoing developments on the web. There is, then, a feedback phenomenon which means that the internet has such an influence on people that it cannot be ignored.

On the basis of this analysis, we do not predict a very bright future for the conventional media. A well-known philosopher gave a paper in Barcelona in which he argued that, in the United States, much of the written media which succeeds in surviving the current crisis will be owned not by conventional companies but by foundations. These organizations guarantee the right to be informed much as if it were a public service.

It should be noted that, while we recognize the value of journalists as mediators, we question citizen journalism and social networks, we fail to recognize the appearance of a universal mediator of knowledge: Google, which has a virtual monopoly.

In conclusion, we would note that scientific communication, like communication in general, exists in a rapidly changing and unpredictable panorama. At every moment, new and unpredicted elements appear, leaving us facing a scenario of uncertainty which threatens the stable system of the social communication media.



## The boom in institutional communication

Johanna Cáceres, *director of Communication at the Catalan Oncology Institute (spokesperson)*

Leticia Costas, *head of Communications at the Instituto de Microcirugía Ocular*

Marc de Semir, *director of Corporate Communication and International Relations at the Corporació Sanitària Clínic*

Carmen Fernández, *journalist at "Diario Médico"*

Xavier López, *student on the Master's Degree in Scientific Communication at the Pompeu Fabra University*

Francesc Villagrasa, *student on the Master's Degree in Scientific Communication at the Pompeu Fabra University*

The conclusions presented here are based on the professional experience of the members of this group; in this regard, it is important to note that all of us, except for two professionals who have not yet completed their training, work in the biomedical sector. The discussion revolved around two issues:

- Can we really talk about a boom in institutional communication?
- Drawing up recommendations for application to the institutional communication deployed by organizations conducting scientific research, which was the goal set for us by the seminar organizers.

## Is there really a boom in institutional communication?

In Catalonia there has been significant growth in the resources allocated to institutional communication by organizations and companies engaged in research: hospitals, universities, research centres and, of course, industry. However, this phenomenon is less marked in the rest of Spain, and varies from region to region.

Scientific communication — designed to make the results of research available to the general public — takes place within the framework of corporate or

institutional communication, and the members of this working group felt that the growth of institutional communication in Catalonia was due to three factors:

- The importance of the biomedical sector to Catalonia's economic, business, scientific and social fabric. This sector has a long history and in recent years has been supported by governmental strategic development plans identifying the biomedical sector as key to the future of the Barcelona region and of Catalonia in general.
- The transfer of competencies for health matters to the regional government and the consequent development of the public and private sectors.
- The professionalization of the management of these institutions (management textbooks present communication as a strategic tool which is a key element of successful management).

## Some recommendations

When we talk about ethics, we are really talking about the values on which the goals of scientific communication are based and which guide our actions when pursuing them.

As noted above, scientific communication is designed to share the results of research activity with a lay audience. Its aim, however, is not to transfer a series of data from group A to group B (nor is it to talk just for the sake of talking, or to release information at random, nor to provide a platform for scientific celebrities).

The purpose of scientific communication is linked to the active operation of the democratic system and can be summarized as follows: enabling, facilitating and enriching the social debate necessary for the taking of informed decisions about research and health care.

Scientific communicators should therefore focus their activities on these objectives, incorporating the values of accuracy, transparency and trust into their work:

- **Promoting the credibility** of the members of the communications team and the strategic nature of their work. Teams are often relatively new, having been created during periods of institutional change, and assuming functions which were not previously performed within the organization or which were performed by other departments. For this reason, it is important that communication professionals seek to educate people, explaining the value of their work and, above all, demonstrating the added value they provide for the company: internal communication is an essential element of institutional communication policies in general, and of scientific communication in particular. Otherwise, companies will question the cost-effectiveness and the relevance of communications teams and may even wonder whether there is any need for them at all. The credibility of the team depends to a large extent on the issues identified below.
- **Senior management.** It is essential that any institution's communications manager should belong to the senior management team, participating in committees where decisions are taken and answering directly to general management. Where this is not the case, it makes it very difficult to develop an appropriate communication policy which is consistent with the organization's strategic objectives. At the same time, it undermines the authority of the communications team in performing its job and working with other professionals.
- **Professionalization and journalism.** Like any area, institutional communication in general and scientific communication in particular require professionals with specific training. Otherwise, it is likely that the work will add little value to the organization and that communications professionals will contribute little or nothing to their institution. In this respect, it is important to defend the journalistic role of the communications team and, in particular, of the team leader. As such, the team leader must have a detailed understanding both of the institution itself and of the context in which it operates, he or she must be curious about what occurs there, connect with other professionals, prioritize information and "create" news, act as a gatekeeper (screening what is of relevance for the general public, for other professionals,

or for the scientific community) and align this communication with the "editorial line", that is, with the strategic objectives of the institution or company.

- **Portfolio of services.** The communications team may go by any one of a bewildering variety of titles: press office, public or institutional relations, audiovisual communication unit etc. In itself, this is neither good nor bad, but if we take the specific example of the communications unit where we work, then we need to define the scope of the activities for which we are responsible. As a result, we also have to identify what we are not responsible for; otherwise, there is a danger of confusion, frustrated expectations regarding what the communications team can achieve, duplication and overload. In sum, the quality of work declines and productivity falls.
- **Segmenting audiences.** The audience for scientific communication is not a homogeneous mass but consists, instead, of clearly identifiable groups, both internal and external. This diversity means that we need to adapt messages, timings and formats to each, in order to ensure that our communication is effective.
- **Don't rush in.** When presenting new techniques, technologies or drugs, it is important to wait until evaluated results are available, and this can sometimes create conflict with companies' desire for publicity or to project an innovative image. One of the key criteria when deciding whether information is newsworthy is how current it is: "event X occurred today", which, in the case of science, would be "today saw the publication of an article in this or that journal", "today a new technology was introduced", "today a new technique was applied for the first time in Catalonia/Spain/the world", "company X will be the first to ...". In some scientific settings, such as biomedicine, this race to make announcements generates false expectations among those suffering from illnesses which these alleged innovations are claimed to cure. At the same time, it can create public demand which translates into pressure upon the health system which this is unable to meet.
- With respect to the preceding point, it is important **not to be blinded by the reputation of high-profile individuals** — this is not science,

and such individuals (like everyone else) sometimes have new and interesting things to say and sometimes don't.

- **Document the institutional communication policy** in a style manual which, in addition to describing the standards for the visual corporate identity, should also clearly set out the framework for relationships with other players in the communication field: the media (appearance in certain publications subject to payment, leaks, exclusives, access to patients etc.), suppliers (offer or obtain support, establish cooperation etc.), social representation and so on.

## The dictatorship of the scientific journals and open access to knowledge

Norbert Bilbeny, *lecturer in theoretical and practical philosophy at the University of Barcelona*

Màrius Morlans, *president of the Ethics Committee of the Official College of Doctors of Barcelona*

Marta Naval, *journalist with RNE and student on the Master's Degree in Scientific Communication at the Pompeu Fabra University*

Andreu Segura, *head of Public Health at the Institute of Health Studies*

Lidia Vilagut, *biologist and student on the Master's Degree in Scientific Communication at the Pompeu Fabra University*

Scientific journals are a necessary means of transmitting scientific progress to the scientific community and, subsequently, to society via the media. However, the fact that they are necessary does not mean that how they operate is above criticism and cannot be improved. Our working group stressed that the principle of authority on which journals are based does not operate in a vacuum. In order to evaluate the quality of articles published, we need to establish a system which would enable us to monitor and assess the quality of journals. To this end, we suggest assessing the evaluators with the aim of reconsidering the credibility of journals and their editorial criteria. An increase in credibility would give rise to an increase in trust: a key value in scientific communication.

We believe in the importance of such audits or evaluations of journals because we believe that otherwise there is a danger of them becoming complacent and set in their ways. Factors which can affect quality include:

- **Improving the peer review system.** Which researchers review articles? Are they qualified to perform this work?
- **Focus of published work.** It is easier to find positive articles than negative ones. Experiments which do not work out as the researcher had expected find little space in journals. It should also be noted that corrections are not as frequent as could be hoped.
- **Distortion of impact.** The desire to make a professional impact, while understandable, may at times mean that the article lacks social rele-



vance. In this case, where an article merely reflects a desire to make the author the focus of attention, we believe that publication is inadvisable.

- **Corporatism.** It is important to know which editorial group or organization produces the journal, because its interests may influence the content.
- **Limitation of term in office for editors in chief.** We suggest that the editors of scientific journals should not be allowed to remain in post for ever, and that they should only serve for a maximum of 8 years.

We would like to stress two key elements for the healthy operation of scientific journals: a code of ethics and the declaration of interests.

## Open access to knowledge

If we ask whether we believe that access to knowledge should be free and universal, our answer would be yes. Communication is inherent to scientific discoveries and, therefore, should not be hindered in any way.

The problem is how to guarantee this free knowledge. At the moment, journals are funded in three ways: through subscriptions, from payment by researchers so that their work is published, and through advertising.

None of these three funding systems can guarantee fully open access, given the cost of the publication process. Advertising may generate conflicts between the advertiser and the scientific content of the journal. In fact, just as is occurring in the newspaper industry, so the journal sector is undergoing changes. Many experts, above all editors, are questioning whether it is sustainable to make daily newspapers freely available. We didn't reach any conclusions about the funding of journals, far less about their transfer to the internet to provide free and open access.

We also wanted to stress the importance of learning to read scientific journals and review journals.

With regard to the role of journalists, we need to promote ethics within the profession. It would also be good if there were greater scientific knowledge to help improve the quality of the information appearing in the media.

## INDIVIDUAL CONTRIBUTIONS

### Ethics 2.0 of scientific communication

*Cristina Aced, journalist and communications consultant*

Although it was not one of the aims of this seminar to discuss the web 2.0, this issue has nevertheless proved to be one of the key issues under consideration today. As the members of the working group on institutional communication noted, one of the new functions of communications departments is to manage the organization's internet presence. Just as they already do in an offline context, so the members of such departments now also have to watch out for the company's reputation online: that is, they have to manage its digital presence.

The person who performs these functions is sometimes called the community manager, but what is really important is that the functions are performed in a strategic manner. It's easy to create a blog or a YouTube channel or to have a presence on social networks. What is far more difficult is to do this in a coherent manner, with clear objectives and a precise purpose which form part of a social media strategy. There is no point in the communications department of a research centre creating a blog if nobody knows who will publish on it and on what topics. For this reason, before launching yourself into the 2.0 world, it is important to listen, to see what other people are saying about you on the internet and who they are, and, in a second stage, to enter into dialogue, either on other people's platforms (through comments) or on your own, in the light of careful reflection upon your own objectives.

## Face to face

2.0 platforms make it possible to reach the public directly, without intermediaries. Futurity.org is a good example of this, and puts universities in touch with society, without the need to pass through the filter of the major scientific journals. These tools also enable the public to raise their voice and be heard, through sites such as PatientsLikeMe.com, where patients can share their experiences with other patients in the same situation. Initiatives such as

these show that there are unmet needs, and this is why users take advantage of these tools to create and share what they do not find on other platforms.

These needs and the wish to share are key to the success of 2.0: without these sentiments it is very difficult to get a participatory initiative to work. It's easy to create a virtual network, technologically speaking, simply by using one of the free technology platforms which exist for this purpose; what is really difficult to do is to create a community, a feeling of belonging among the members who form part of it. This can't be forced, and must instead arise naturally, and should be the point of departure for any virtual community.

## New opportunities

All change generates fear, and this fear of the unknown is perfectly normal. In response to web 2.0 we can adopt two postures: we can deny it (despite which, it will continue to exist) or we can take advantage of the opportunities it offers, including in the field of scientific communication. This is the great challenge which faces us in the immediate future. The digital sphere is not some separate world; it is part of our day to day reality. If many readers, users and members of the general public are present (and actively participating) in the web 2.0, should we really pass up the opportunity of talking to them? Would it not be better to take the initiative ourselves than to allow others to speak for us?

This does not mean lying or manipulating, but being proactive in managing our reputation and participating on the web. We cannot prevent others from talking about us, but we can contribute our own point of view to the conversation, making sure we do so in a transparent, accurate and respectful manner, as we do in the offline world. Ultimately, the internet is not so different from the outside world, and the best and safest approach to it is to apply common sense. At root, the ethics of online communication is not so very different from the ethics of online communication.

## The flu crisis

**Andreu Segura, Public Health doctor and president of the Spanish Society for Public Health and Health Administration**

*(The two texts which follow were written at the height of the swine flu crisis of Autumn 2009.)*

## Flu and social panic

As a public health professional, I am concerned at the manner in which the mass media report deaths caused by the new variant of the influenza A virus. They treat them one by one, providing details of each individual case, doing little to enhance our understanding of the process while exaggerating the real impact of the illness and risking promoting social panic which could be more harmful than the flu pandemic itself.

I don't consider myself competent to judge the information interest of such events, but I find it hard to imagine similar media coverage of the thousands of deaths caused by seasonal flu each year. I imagine that the explanation of this unequal treatment lies in the fact that this flu is different from the normal variety, even though we do not know how different it is.

Until now, the clearest difference is that the capacity of the current virus to spread, at least during summer, is higher than that of the flu viruses circulating in recent years, something which is doubtless due to the susceptibility to infection of the young, a group who have also played a decisive role in the initial propagation of the virus.

This is the most important difference to date between the pandemic flu and seasonal flu. Its impact on healthy individuals is something it shares with usual epidemics, and it is not unusual for the common flu to cause complications in pregnant women. The nature of the associations which may exist between personal characteristics, the risk of infection, and the risk of presenting complications all remain to be determined.

Fortunately, the virulence of the new flu virus is limited and, although nobody can guarantee that it will remain so benign, nor can anyone prove the

contrary to be the case. The information available for countries which are getting to the end of winter would suggest that it is to be expected that the proportion of serious and lethal cases will not exceed that of seasonal flu. Nor have we seen significant changes in the nature of the virus. The experience of countries in the southern hemisphere also provides examples of different ways of responding to the situation, ranging from panic to calm.

The majority of flu infections which will occur in the coming months will, then, be light and moderate with patients making a spontaneous recovery. Indeed, many will be asymptomatic infections which go unrecorded; some, however, will be more serious and, unfortunately, as occurs every year, there will be deaths either as the direct or indirect result of the infection.

If the number infected is high, even if the proportion of serious cases is small, in absolute terms it could amount to a significant figure, placing significant demands on health professionals and the health system; it would be irresponsible to cause the system to collapse under the weight of unnecessary demands. Yet such demands often increase in panic situations, and can lead to the adoption of solutions which have not yet been shown to be effective. Doing something is always reassuring, even if there is no reason to believe that what we are doing is of any benefit, and may even be harmful. It is logical to use antiviral drugs, but not indiscriminately when their therapeutic capacity is limited, they are not free of side effects, and may generate resistance. The expectation of a vaccine is reasonable, but not so reasonable is blind faith in the protection it offers, without any evidence of its efficacy and safety; and above all when many southern hemisphere countries have dealt with the first wave of the pandemic without vaccines.

A significant proportion of the population has experienced more than one flu pandemic and many seasonal epidemics without recourse to specific drugs. There is no need, then, to become obsessed, but nor should we be resigned. It is important to establish reasonable protective measures which reflect the scale of the threat, and to perform a sensible analysis of risks and benefits for each action.

Returning to my initial point, media treatment of the development of the pandemic will have a decisive influence on the quality of the health and pub-

lic response to this health threat. And if we are not careful — and this does not mean being secretive or paternalistic — then media treatment will create a panic whose consequences could be worse than those of the flu itself. True transparency does not need to be in conflict with responsibility.

## Flu and social panic

Fortunately, the new flu virus has to date proved to have very low virulence, and this is likely to continue throughout the first wave of the epidemic. It is therefore important that the prevention and control measures reflect this, to reduce to a minimum the inevitable negative impacts which otherwise may be worse than the damage they are designed to prevent.

In this context, the media has a major responsibility when reporting on the situation, as do politicians (both in government and in opposition) with regard to ensuring that their response is appropriate. Given that the epidemiological situation does not require the adoption of urgent or drastic measures, any monitoring actions should be adopted calmly and sensibly.

This monitoring has been sufficiently sensitive to detect an outbreak of the epidemic in the military barracks at Hoyo de Manzanares, which began with a mild, non-specific respiratory infection, without any known contact with individuals who had been in Mexico, and whose clinical characteristics did not match the accepted definition of suspected flu cases.

The decision to conduct a virological investigation was taken in light of the international epidemic and due to the fact that new cases continued to appear and to receive medical care under conditions in line with the recommendations of the Spanish and international health authorities in the current epidemiological circumstances.

Of course, while the lab results were being awaited, more drastic isolation measures could have been imposed, such as suspending the visit of a group of schoolchildren to the military site, but given the circumstances and the distance of visitors from the potential infection sources (the infected soldiers) this would not appear to have been essential.

At this time, as the World Health Organization (WHO) has stated, the main purpose of health actions should be to minimize the consequences of infection, given that it is not realistic to attempt to stop the spread of the virus. These consequences include making proper use of health resources and not unjustifiably undermining the credibility of the health authorities. Because, while controlling the future development of the epidemic depends on the competency of the health services and the public health system, without the trust of the population this will be impossible.

Using this episode for short-term, partisan gains exposes us to the risk of helping undermine those responsible for public health in local, regional and state government, and this is not a luxury we can allow ourselves in the event that the next season of flu requires greater efforts on the part of the health authorities.



## Seminar participants

- Cristina Aced, communication consultant and contributor to the Scientific Communication Observatory of the Pompeu Fabra University.
- Magda Bandera, journalist with *Público*.
- Norbert Bilbeny, lecturer in theoretical and practical philosophy at the University of Barcelona.
- Johanna Cáceres, director of Communication at the Catalan Oncology Institute.
- Victòria Camps, president of the Víctor Grífols i Lucas Foundation.
- Maria Casado, director of the Bioethics and Law Observatory at the University of Barcelona.
- Gonzalo Casino, health correspondent at *El País*.
- Marta Ciércoles, health correspondent at *Avui*.
- Leticia Costas, communications manager at the Instituto de Microcirugía Ocular.
- Carmen Fernández, journalist at *Diario Médico*.
- Francisco Lupiáñez, researcher at Institute for Prospective Technological Studies (IPTS).
- Josep M.<sup>a</sup> Martí, dean of the College of Journalists of Catalonia.
- Miquel Àngel Mayer, director of the Medical Website at the Official College of Doctors of Barcelona (COMB).
- Màrius Morlans, president of the Professional Ethics Committee of the COMB.
- Gemma Revuelta, assistant director of the Scientific Communication Observatory at the Pompeu Fabra University.
- Andreu Segura, head of Public Health at the Institute of Health Studies.
- Marc de Semir, director of Corporate Communication and International Relations at the Corporació Sanitària Clínic.
- Vladimir de Semir, director of the Scientific Communication Observatory at the Pompeu Fabra University.
- Students on the Master's Degree in Scientific Communication at the Pompeu Fabra University: Laura Chaparro, Xavier López, Marta Naval, Teresa Sánchez, Lúdia Vilagut and Francesc Villagrasa.

## Publications

### Bioethics monographs:

25. *Ethics: an essential element of scientific and medical communication*
24. *Maleficence in prevention programmes*
23. *Ethics and clinical research*
22. *Consent by representation*
21. *Ethics in care services for people with severe mental disability*
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. *Addressing the problem of patient competency*
13. *Health information and the active participation of users*
12. *The management of nursing care*
11. *Los fines de la medicina* (Spanish translation of *The goals of medicine*)
10. *Corresponsabilidad empresarial en el desarrollo sostenible* (Corporate responsibility in sustainable development)
9. *Ethics and sedation at the close of life*
8. *Uso racional de los medicamentos. Aspectos éticos.* (The rational use of medication. Ethical aspects)
7. *The management of medical errors*

6. *The ethics of medical communication*
5. *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:

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

### Ethical questions:

3. *Surrogate pregnancy: an analysis of the current situation*
2. *Sexuality and the emotions: can they be taught?*
1. *What should we do with persistent sexual offenders?*

For more information visit: [www.fundaciogrifols.org](http://www.fundaciogrifols.org)

FUNDACIÓ  
VÍCTOR  
GRÍFOLS  
i LUCAS