

THE ETHICS OF MEDICAL COMMUNICATION



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INTRODUCTION

I would like to start by thanking everyone for attending. As a journalist and, more specifically, as a scientific journalist I am firmly convinced of the importance of today's meeting. We will be considering the nature of the communications industry and medical journalism, how information reaches us, what sources it comes from, and what problems this entails. All of these issues have an impact on society as a whole, and upon medicine in particular, and this is why as a journalist I feel that it is so important for us to analyze and discuss them. However, it is not just as a journalist that I would like to thank you for attending, but also in my role as Local Councillor and Chairman of the City of Knowledge in Barcelona. As you may know, the main goals of this initiative are to monitor and analyze issues relating to science, technology or medicine in our city and our society, and this remit includes improving the information channels available to the citizens of Barcelona.

There was also a third reason for organizing this event. The two issues we will be addressing today – communication and medicine – will have a significant presence at the 2004 Forum of Cultures. The programme of conferences and debates for that event includes the 7th Congress of the international network for the Public Communication of Science and Technology, with a special focus on the impact of different cultures on the ethics of scientific knowledge and communication. As a result, far from being an isolated event, today's meeting takes place within the framework of a global strategy which brings us together with the Víctor Grífols Foundation and other institutions in our city.

I would like to introduce today's topic with a few personal reflections drawn both from my professional practice and from my experience as a teacher of scientific journalism at the Pompeu Fabra University. The world of scientific and medical communication is not immune to the more general phenomenon of the increasing sensationalization of information. It is worth asking whether this is due to the influence of audiovisual media, primarily television. The way in which television programmes are produced today also leads to a degree of triviality or, to put it another way, a tendency to oversimplify messages. In this regard, the concept of "fast thinking", developed by the French sociologist Pierre Bordieu, would seem to describe our current situation: fast, short, anecdotal messages, with little analysis of the information

itself. A significant indicator of this trend comes from the *Quiral Report*, which we produce at the Scientific Communication Observatory. During the last three years the number of medicine and health-related items published in the five most widely read daily newspapers in Spain has doubled. The number of news items, letters to the editor, editorials and the like has doubled! And this profusion of news has gone hand in hand with a clear trend towards sensationalism. Put in other words, we are suffering from a combination of communicative bulimia and informational anorexia, and this is something we would do well to consider carefully, as the consequences could be serious.

The central topic of today's discussion is medical communication, and in particular communication through scientific journals and the media. I hope that we will consider the real ethical challenges which exist in the transmission of medical information and of general scientific information, regarding the role of institutional communication, corporate communication, journalists working for large media groups, etc. But we also need to consider many other aspects of communication, such as doctor-patient communication and how this has changed in the light of the spread of new information technologies. Is the medical community prepared for this new type of patient, who comes to his doctor's appointment armed with vast quantities of information gleaned from the internet?

And we will also discuss the closely-related problem of how the scientific message is repackaged as a communicative message for society. For example, over recent years we have seen how scientific journals have gradually moved beyond their original specialist communities to "offer themselves" to the mass media. Their information, which was once restricted to a small and specialized professional audience, is becoming more widely available, due primarily to the huge impact of press releases and a range of other communication strategies employed by these publications in their dealings with the mass media. Some scientific journals virtually have their own press agencies. In another example, which also relates to the role of scientific journals, a few days ago thirteen journals made a joint declaration to defend the independence of both authors and publications from the big interests of the multinational pharmaceutical groups. So we are facing a moment of change and of debate, both in the wider sphere of communication in general and within the medical communication community.

Our aim today is to analyze all the aspects of scientific and medical communication, and to achieve this we have invited two speakers who I am sure are already well known to everyone here: Dr. Miquel Vilardell, head of the Internal Medicine Service at Vall d'Hebron Hospital and director of the journal *Medicina Clínica*, and Dr. Gemma Revuelta, assistant director of the Scientific Communication Observatory at the Pompeu Fabra University.

VLADIMIR DE SEMIR

Local Councillor and Chairman of the City of Knowledge
Department of Barcelona City Council and Member of the Board
of Trustees of the Víctor Grífols i Lucas Foundation

THE ETHICS OF MEDICAL COMMUNICATION

Dr. Miquel Vilardell

When we consider the ethics of medical communication, we need to start by considering whether there is indeed a problem with the medical communication which reaches the audience of the mass media. To start with, I have picked out the following quote, from one of Spain's leading scientific communicators, Josep Lluís de la Serna, well known for his work with *El Mundo* newspaper. In a short report entitled *Scientific and social challenges*, published in 2001 by Farmaindustria (Spain's association for the pharmaceutical industry), he wrote: "Unfortunately, not all the biomedical information which appears in the mass media is true, but above all it is not treated with the rigour, impartiality and responsibility which should characterize serious journalism. It may be distorted by manipulation and by conflicts of interest." These are the words of a scientific communicator, and they prompted me to ask: "Why does this happen, and who are the actors in this drama?" Well, firstly, there are the scientists and doctors who produce and transmit specialist scientific information. Then, there are the publications where this scientific information appears, the respected scientific journals which employ a peer review process. And finally, there are the recipients of the information. I would like to consider the nature of all these actors in the drama before us.

What are the aims of these scientists and doctors? According to Beaucamp, scientists meet, transmit information and educate people in order to bring about advancements in knowledge and to promote the social good, while doctors meet, transmit information and educate people to promote the health of service users, patients or the sick. So I ask, when we doctors give information to our patients, what do we take into consideration? The teachers of bioethics ask what it is that patients want to hear. We need a set of principles to govern the information we give to the sick. What is it that service users (sick or not, but suffering from a physical or mental health problem) want to know?

We must start by looking at the principles which underpin the information we provide to patients. Firstly, there is the principle of non-maleficence with which we are all familiar: the principle that we should not provide information which could harm the health or well-being of the recipient. It is unclear whether this could be usefully applied to the media, as information which is valuable may have a harmful effect on the physical or mental state of its recipient. The second principle is that of parsimony: that we should provide information about the facts of which we are sure and for which we have scientific evidence,

and, where such evidence is lacking, we may need to avoid giving this information, at least to service users who are ill. And finally there is the principle of positive information. The doctor should provide all the information, but should emphasize the positive aspects.

These are things we already know and apply when providing information, so what is going on? Sometimes, one-sided information is provided to an audience which is poorly informed about scientific issues in general, and which may know nothing about the particular issue in question. Secondly, many written reports contain both concepts and terminology which readers struggle to understand. In this context, it is easy for them to misinterpret scientific information, and the matter is made worse by the fact that much of what is published is “junk science”; at best trivial and at worst harmful. At the same time, scientists themselves sometimes rush to publish and may not tell the whole truth about what they have discovered or done, and at times they may mishandle the information they release to the public.

So it may be that scientists and science in general are failing to achieve their goals. Why might this be happening? Because the media don’t collect the information properly, because they use unreliable sources. Where should the mass media get their scientific information from? Only from serious journals, from those which use a peer review process to ensure that all scientific findings have been externally evaluated. Because journals which do not have a peer review process lack credibility. Of course, we can question whether there may also be significant biases even in those journals which use peer review, but to start with it can be argued that newspapers and the mass media should collect information from reliable sources such as these.

Sometimes, as Vladimir de Semir has pointed out, it is all too easy to publish sensationalist information, and at other times we may omit important parts of the information because there are elements we have deemed unimportant. All of this means that our information sources must be precise and reliable, they must be validated and carry out thorough external reviews, they must give a balanced presentation of the scientific information they provide; and, most important of all, scientific journalism must be professionalized. Not everyone has what it takes to be a scientific journalist, because you need a good scientific understanding of the knowledge you are transmitting, and this often means that one has to have specialized in a particular field.

Let us consider the role of the scientist, because a large part of the problem arises from the poor quality of material provided by scientists or from scientists rushing to release information. We all know that there are a few scientists who continue to use questionable practices, such as plagiarism and the falsification of results, which sometimes get through the peer review process. And we have also seen how scientists often appear in the media with their findings, creating an obsession with fame. Scientists should remember that science is not an individual endeavour but is the work of an interdisciplinary team. I don't believe in individual research and lone researchers. To bring an idea to completion requires contributions from a range of disciplines, and that makes teamwork essential. The pressure for early publication comes from the competitive nature of the scientific world, the need to find new funding sources for one's research, the desire to expand one's CV, and the fact that universities rate staff on the basis of what they publish. "If I don't publish, I don't exist." "If I don't appear on the internet, or I don't appear on sources such as Medline, I'm just a nobody." And this curriculum-building may give rise to improper practices. The resultant rush to release discoveries which turn out to be nothing of the sort can create problems for the mass media. At the same time, scientists, logically enough, have to find sources of funding, and this at times means they have to have close links with the pharmaceutical industry and other commercial players. I will discuss this briefly later. And, finally, scientists have very close relationships with the editorial committees of journals, and this can be a significant source of bias under certain conditions.

All this leads me to the conclusion that we need to find a way of managing knowledge, that we need to create knowledge management agencies. There should be someone with all the knowledge which is being created who processes it, assesses it, and makes it possible for the public to assimilate it, and this is a job for experts. Without such knowledge management experts, it is difficult for the information to reach the end users properly. Now, you may say that nowadays information is available to everyone, and this is clearly true: people can get all the information they want over the internet. However, I think it is wrong to believe that this means that people are better informed, as Vladimir de Semir said. I see patients with all the prostate cancer protocols you could wish for, but who still don't have a clue. And if it is easy enough to find specific mortality or morbidity statistics for cataracts or prostate cancer, it is far harder to identify the morbidity of chronic fatigue syndrome. You might be able to find the mortality-morbidity figures for cataracts in a specific centre,

but finding more general information will be difficult. And we should not forget that much of the information on the internet is inaccurate. For example, 6% of the cancer-related websites we studied contained errors, and 42% of all the information about cancer had not undergone peer review or been assessed by a committee of experts, but there it was. You may say this is not important but, as Sivil Bierman argues, errors really do matter, and can have a devastating effect. So, even if errors are not that common, where they do exist they can have a negative effect.

Medical practice changes, and nowadays everyone uses scientific evidence and clinical protocols. It is no longer enough for doctors to draw on their own experience, to say, “I’ve seen lots of cases like this, and I think ...” There is less variation in clinical practice; there is a protocol for the treatment of prostate cancer, and a protocol for breast cancer and it doesn’t matter if someone is a great doctor or a great scientist; he or she still has to follow a clinical protocol which has been validated by meta-analyses. Individualism in clinical practice is no good. In other words, the paradigm for modern medicine is evidence-based practice and that means that scientific journals acquire more importance, and so do you, because doctors can no longer do what they want but have to follow a document, because they can be held responsible for their decisions.

This means that when scientific journals conduct their peer review process they must take ethical principles into account. These must include impartiality when accepting scientific work, confidentiality regarding its contents, and resolving any conflicts of interest prior to publication. Credibility depends above all on whether conflicts of interest have been resolved. If you can’t tell me how the conflict of interests relating to a paper or a clinical trial has been resolved, if you can’t tell me who funded it, whether the principle investigator is free to publish both positive and negative results, if only he is familiar with the statistical data and nobody else has evaluated it, then the work will lack credibility, even if it is actually worthwhile and important.

There must be transparency in the review process, and even despite this, biases may still exist. One source of these is the editorial committee. There may be both positive and negative inducement, and this can lead to errors in both directions. External reviewers can also be a source of bias when these are only based in Spain, and the reality is that this is usually the case. We all know each other; we are familiar with all the scientific groups in the country, and its’ members know one another. As a result, we need external reviewers who do

not belong to the same scientific community as the author. So we need respected external reviewers who have already published in the subject area and whose names appear in a database of leading researchers in the relevant field. I would argue that this is a very important task. The reviewers of most journals still have a lot to do to tackle these sources of bias.

I would also like to reiterate what Vladimir de Semir has said. Reviewers tend to reject articles which propose innovative ideas, because sometimes the scientists performing the reviews are not very interested in innovation, and they say, “I’m not sure about that, be careful, give it a while to bed down, and then we’ll discuss it.” So one criticism of peer review, of external review, is that it inhibits innovation. It may be that the use of new internet networks, web-based review, open online review bringing together all the people I mentioned at the start, offers a way of correcting this bias against innovation.

Another issue is that articles published in Spanish face a big hurdle, because anything not published in English loses out. The journal *Medicina Clínica* is number thirty-six in the world and is the leader in Spanish, with an impact factor of 0.75. One might think that publishing in English would increase our impact factor, but that’s not the case because the people who cite us are usually scientific authors writing in Spanish. This is another important bias, and makes things difficult for research in Spanish, although I think we will ride the problems out.

There are also institutional influences. Sometimes it is easier for information which comes from a well-known academic centre to make it into the media than it is for information produced by a small research centre based in a small hospital or university. So we should also be aware of this institutional bias.

And finally we must consider the industry which funds the majority of research. For example, in the United States the biomedical industry invested 55 billion in research in 2000, and 70% of this money was destined for clinical trials. By way of comparison, the US federal government invested 25 billion. As you can see, the pharmaceutical industry invested far more than federal government in research, and this was channeled primarily into clinical trials. This is clearly very significant and, while I don’t want to suggest that clinical trials are not important, because they can have a great practical impact and bring immediate benefits, we must be aware of this bias. So we

need to consider the nature of the relationship between scientists and the industry which funds them. This should be very clear. Does the industry seek out a principal investigator, or is it the principal investigator who has the idea and then raises the funding? We all know the answer. Most of the time, it is the industry which seeks out a particular principal investigator and this is logical enough, because they want to find the person with the best scientific qualifications to conduct the research, but it also brings the risk of bias. We therefore need to study all the clinical trial data with care, and the principal investigator must be responsible for supervising the clinical trial, he must handle the data, perform the statistical analyses, and tell the public about the findings and whether or not he has been subject to any restrictions.

As Vladimir de Semir has said, the editors of these journals now require that the journal be informed when work which relates to a clinical trial is submitted. They need to say who the principal investigator is, where the funding comes from, and what is the role of each member of the team which has authored the study. This issue of authorship is important. It is not acceptable when a scientific article is published for the principle investigator's boss to be the one who appears in the media. The boss may be a knowledge manager, a finance manager, a senior director of a knowledge centre, but it may also be that he doesn't know much about the specific research topic, so it is the principal researcher who should appear in the relevant scientific publication. As far as I'm concerned, these new requirements from journals are very welcome; I think they're very important.

In Spain the scale of problems relating to the publication of clinical trials is not so great, because the industry is small and the majority of clinical trials are conducted by large multinational companies which publish primarily in English language journals. So in Spain, although high quality clinical trials are undertaken, very little is actually published in Spanish journals. I believe that in the future there will be more transparency, greater clarity in the area of publication, and that scientists will be open to information, and will know how to educate people and be able to do so with absolute freedom. And the new digital communication media will allow everyone – users, external reviewers, scientists, doctors, editorial committees, the media – to work together in our endeavour of communicating with society, identifying what constitutes reliable, comprehensible scientific information.

THE ETHICS OF MEDICAL COMMUNICATION

Dr. Gemma Revuelta

- 1. Do we need a specific ethical approach for medicine and health in the media?**
- 2. From hope to false expectations**
- 3. From information to opinion**
- 4. From whistle-blowing to social panic**

Medical communication is usually divided into two apparently separate processes: medical or scientific communication in the strict sense (scientific journals) and the social communication of medicine and health issues (the mass media).

Miquel Vilardell has just given a detailed account of medical communication in the strict sense – that is, the communication which occurs within and for the benefit of the medical-scientific community – and this requires a specific ethical approach. In my contribution I will focus on the second scenario, represented primarily by the mass media.

It should be noted, however, that this distinction between two spheres – the scientific and the social – although convenient, is a somewhat artificial one, and that they are interlinked with and influence each other in far more ways than is immediately apparent. In other words, medical communication cannot simply be summed up as “journals = scientists for scientists”, and nor can we view social communication merely as “mass media = journalists for the general public”. On the contrary, the two processes are closely linked, and many more actors than just scientists and journalists have a significant influence on the final outcome. These include everyone who is involved in or influences the decision-making process (senior managers at R&D institutions and centres, owners and managers of the mass media and their business groups, the editorial managers of scientific journals, representatives of public authorities, etc.); business communication professionals (staff at the press offices of scientific journals, research centres, hospitals, other health institutions, and the authorities) and the staff who work in the marketing, management and finance departments of these institutions.

In other words, the reality is far from simple and operates more as a network of reciprocal influences than as a one-way flow from the medical community through the mass media to the general public.

1. Do we need a specific ethical approach for medicine and health in the media?

Consideration of the ethical aspects of social communication and the mass media is as old as these phenomena themselves. As a result there are a range of ethical instruments which have an impact on the mass media: from the democratic legitimization of specific rights and duties (the right to information and to freedom of the press are well-established principles in most democratic countries), the existence of professional codes of practice accepted by professional associations, the existence of bodies and associations for professional self-regulation and, on a more practical level, the inclusion of codes of ethics and “good practice” in journalism style manuals.

At the same time, current concepts of journalistic ethics includes not just media managers and the journalists themselves, but also information sources and those social agents which influence mass communication (Josep María Casasús, “El rigor y la ética de la enseñanza del periodismo [*Rigour and ethics in journalism training*] in *Estudios de Periodismo* no. 1, pp 26-27).

Recognizing, then, that the debate about the ethics of communication is far from new, the question I would raise is whether health and medicine raise specific issues compared to the other issues, news items or information dealt with on a regular basis by the mass media. The following example will clearly illustrate the nature of the question. Media theory recognizes that the process of selecting news items is neither so “intuitive” nor so spontaneous as is often assumed and that, on the contrary, it is highly structured (Denis McQuail, in *Mass Communication Theory: An introduction*, Sage, London, 1994) and depends on a range of factors: values which are intrinsic to the information itself, organizational factors etc. Just as those events which occur in places which are near or easily accessible to editors are more likely to become news, so certain intrinsic characteristics of the information are also associated with greater “newsworthiness”. These include the scale or magnitude of the event, negativity, drama, action and the degree to which it accords with prior experience or information. This framework within which news items are selected applies to all types of information, ranging from politics and economics to crime and sport, and includes health. Applying our initial question to the specific issue of the

selection of news items, are the implications and consequences of the normal news selection process different (more serious, greater, more significant etc.) in the case of health and medicine? Does this process raise specific ethical issues?

The approach we have applied to the production and selection of news items can also be applied to the other communication processes: the selection of information sources, the investigation of accuracy, the presentation of information, reception by the audience and so on. The examples I am going to discuss below are real, if at times extreme, cases which illustrate a range of problems in the social communication of health and medicine. I hope they will help to provide the basis for a far-reaching discussion during the second part of today's event.

2. From hope to false expectations

One of the main results to come out of various studies into media coverage of medical and scientific research is the tendency to present this in terms of “progress”, “advance”, “development”, “hope”, etc. This type of approach reflects a feeling of belief in scientific progress as offering the possibility of improving our quality of life, alleviating or curing illness, and increasing human life expectancy. In some cases, however, scientific news not only encourages hope but generates high and often false expectations. Conclusions for which there is no firm scientific basis are advanced, the results themselves are exaggerated or generalized despite the fact that the conditions under which they were produced do not support such extrapolation, or the future applications of a “discovery” are discussed without making it clear how much of this is based on fact and how much of it is mere speculation.

The media coverage of the research of Judah Folkman in *The New York Times* of 3 May 1998 (for more detail, see “The New York Times cures cancer” by G. Revuelta, *Quark*, No. 12, Barcelona 1998) provides a clear example of how the combination of a variety of resources and journalistic approaches can create false expectations among a very vulnerable group: cancer patients with few treatment options. The report, which appeared on the front cover of the paper's Sunday edition, recorded the achievements of a team of

researchers led by Dr. Judah Folkman, with a group of substances whose mechanism of action focused on reducing the blood supply to solid tumors. Not until some way into the article was it made clear that these substances were still at the animal experimentation phase, and the impression was given that within a couple of years (in other words, by 2000) the drug would be applied to humans. The scale of the discovery was emphasized by the words of Nobel Laureate James Watson, who was quoted as describing the research in the following terms: “Judah is going to cure cancer in two years.” The fact that the article was signed by an experienced scientific journalist, together with its having appeared in a serious, influential newspaper, did the rest. The next day, the world’s media reported the news. Only later did it transpire that there was a complex conflict of interest behind the information, that Watson had never uttered the words attributed to him, and that the only conversa-



THE NEW YORK TIMES, 3 may, 1998



The New York Times, 3 May, 1998



tion regarding it had taken place at an informal dinner and was strictly “off the record”. The other media strongly criticized *The New York Times*, and the paper finally issued a retraction. In the meantime, not only had the share price of the company responsible for the research risen sharply, but many cancer centres had been swamped by patients asking to undergo the treatment, whatever the price.

The line between hope and false expectation is a difficult one to draw, not only for editors but also for scientists themselves, who may be brimming with enthusiasm about work to which they have dedicated years of their lives; for politicians, who are keen to demonstrate to their voters just how well their tax money has been spent; for companies eager to reap profits, and so on. It is equally difficult to identify when research into a new pharmaceutical product becomes a news item of public interest. Should the results of research only receive coverage once they are at the animal experimentation stage? This is not an easy question to answer, particularly given that the decision about when and how to cover such information depends more on organizational factors (such as whether or not there is a press office, personal contact between the researcher and the media, the business interests of the company which owns the marketing rights, etc.) than on criteria relating strictly to the benefit of this information to the public.

The announcement of the draft of the human genome is another clear example of the thin line between hope and sensationalism. “We are learning the language in which God created life,” was one of President Clinton’s most widely quoted remarks in the press when the genome project was presented. Other expressions used at the time show just high the expectations surrounding this announcement were. “It will enable the prevention of 6,000 hereditary diseases,” stressed *El País*, while *The Times* described it as “Opening the book of life”. The excessive use of hyperbole by the information sources themselves, and a high-impact communication strategy (an international press conference with the US president and the British prime minister as spokespeople, together with the lead researchers) were followed by massive media coverage. Is this hope or unfounded expectations? Optimism or sensationalism?

3. From information to opinion

The search for objectivity, which is what distinguishes news from fiction or comment, is a goal which by its very nature can never be fully achieved. The concept of “reality” is itself an abstraction which is difficult to define. In the realm of social communication, subjectivity is a feature of every dimension of the process, from the personal opinions or beliefs of the scientific informer to how audiences interpret the news items they receive. And the way in which the media shapes the information adds a further layer of subjectivity.

In order to limit as far as possible the effect of the “mediator” on the “message” and to respect the objectivity of the facts, the quality media usually clearly separate information from interpretation or opinion. What happens in the field of medicine and health? In this field, the problem lies in the fact that the information – above all that which refers to research – often has little meaning for the general public. The what, who, when, where and why which are usually sufficient for other types of information are not enough to explain the real meaning of reports of scientific information. In these cases, it is often necessary to ask “what ... for” (“The draft of the human genome is being presented ...” What is it being studied for?; “A new path of action of a substance has been discovered.” What application will it be used for?). The “what for” elicits the context required to make sense of much scientific-medical information, but also requires the inclusion of a judgement, an interpretation, an opinion. And this, once again, opens up a long-standing controversy. Should we mix opinion with information? Can the two be separated? Is it possible to provide scientific information without having recourse to opinion, even if only to contextualize the implications of the facts being reported?

The following example illustrates how asking the necessary question “what ... for?” when reporting scientific research may introduce a significant subjective element. The presentation of the “first genetically modified monkey” was reported as follows in the Spanish newspapers *ABC* and *El Mundo* (12-01-2001): The headline in *ABC* was “First GM monkey speeds up design of new human therapies,” while *El Mundo* published under the heading: “First GM monkey opens door to manufacture of designer humans.” The two newspapers, then, gave a very different account of the situation. While the reader of *ABC* may have come away with the impression that the experiment

El primer mono transgénico abre la vía para fabricar seres humanos a la carta

El mono nacido en un laboratorio de Oregon lleva el gen de una médula cordal

30

EL MUNDO, VIERNES 12 DE ENERO DE 2001
SOCIEDAD

El primer mono transgénico abre la vía para fabricar seres humanos a la carta

Se usó un gen humano llamado "ANDI" para crear un mono transgénico. Este animal, a su vez, servirá como modelo para estudiar el desarrollo de enfermedades humanas y para probar nuevos fármacos. El mono transgénico también puede servir como modelo para estudiar el desarrollo de enfermedades humanas y para probar nuevos fármacos.

Primer transgénico

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El mono transgénico creado en un laboratorio de Oregon lleva el gen de una médula cordal humana. Este animal, a su vez, servirá como modelo para estudiar el desarrollo de enfermedades humanas y para probar nuevos fármacos.

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Un hecho fundamental para la biología



SOCIEDAD

VIERNES 12-1-2001 ABC

El primer mono transgénico acelerará el diseño de nuevas terapias humanas

Los científicos necesitaron manipular 244 óvulos para lograr el experimento

ANDI, el primer mono manipulado genéticamente



Los científicos inyectaron, en la superficie de óvulos, partículas de un virus inactivo, que contienen copias de un gen que produce una proteína de color verde fluorescente. Al penetrar en el interior, las partículas liberan este gen que se incorporó al genoma del óvulo.



Los óvulos manipulados fueron luego fecundados con espermatozoides de mono.



Solo uno de los monos nacidos, ANDI, tenía en sus células el gen ANDI.

A partir de 244 óvulos, se lograron 40 embriones que se implantaron a 20 hembras. Hubo cinco gestaciones, de las cuales prosperaron tres.

C. S. M. O. N. A. B. C.

humanos a monos rhesus y estudiar

in question would bring benefits for humanity, the reader of *El Mundo* was likely to have doubts regarding the ethics of genetically modifying animals. The piece could have been titled, “Genetically modified monkey is born and survives.” That would be a neutral, informative title. However, this irreproachable heading would mean little to the average reader, who could not be expected to discover for themselves the reasons for modifying the genetic code of these animals. Someone needs to explain science’s purpose in conducting this sort of experiment, and this is where value judgements come in. Can we maintain the clear line between information and opinion in scientific and medical matters?

4. From whistle-blowing to social panic

Another feature characteristic of medical communication is the impact of certain pieces of information which relate to public health. We only need recall the sudden change in beef consumption as a result of reports of “mad cow disease”, or public demand and consequent mass vaccination against meningitis C (counter to the advice of the time), in response to reports of rising numbers of cases.

On the one hand, we should recognize the many “scandals” and irregular situations in the field of health which would not have been revealed (or, therefore, remedied) had the media not intervened. Indeed, it is a key function of the press to inform the general public about such irregularities and misconduct, as these can affect people’s health. The media have also helped make society aware of the existence of new diseases and how to prevent and control these. The paradigm for this is probably provided by AIDS, a disease which was revealed and explained to society by the mass media (not, of course, without quirks, contradictions, exaggeration and stigmatization). Nor should we forget the influence of the media in developing public health plans and strategies for dealing with AIDS.

However, just as we saw when we discussed hope and false expectations, the line between denouncing a negative situation in the field of health and causing unnecessary alarm (if alarm can ever be necessary) is a hazy one and can easily be crossed in pursuit of the right to information. The problem is

made worse by the tendency of the scientific-medical community to present a “zero risk” model of the health system, with the result that any report of a problem, however mundane it may be, is perceived as critical by a general public which does not accept any sort of system failure. And this also applies to food safety or the environment, to mention two areas which are closely related to health.

I wonder if you recall the “epidemic” of hospital-acquired fungal infections in 1998. In this case, on the basis of a report of the deaths of various patients in a hospital as a result of nosocomial infection, the media across Spain discovered a major source of news. The “media epidemic” spread in a matter of weeks, and the public responded with confusion, worry and alarm. At a stroke, the health system had become risky and unsafe. Do we know how to provide information about the risks inherent in the health system itself? Should negative information be avoided, or should the public be made aware of a “risk culture”?

Another good example of this situation is provided by the outbreaks of Legionnaires’ disease which are detected year after year. The alarm and social confusion appear to be inversely proportionate to the efforts to develop a good communication policy, one which should be characterized not by secrecy and denial of the facts but quite the opposite, as can be seen from a comparison of the recent cases in Alcoy and Barceloneta (for more information, see “Salud Pública y medios de comunicación” [Public health and the media], by Antoni Plasencia and Joan Ramón Villalbí in the 2000 *Quiral Report*). The consequences of the communication policies of the authorities can be clearly seen from this, as can the consequences of communication by the mass media, who are responsible for reporting, amplifying, distorting or silencing certain incidents. Do these public health incidents require special treatment, or can they be treated like any other news item, such as the result of a football match, the statements of a politician, or the latest budget figures?

I would like to end by discussing one more example. A few days ago, a respected Catalan newspaper published the following report on its front page: “Scientists find carcinogenic residues in tap water,” while the subheading added, “Report concludes it causes 600 deaths per year in Spain from bladder

LA VANGUARDIA

VIERNES, 12 DE OCTUBRE DE 2000

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**La Eurocámara
acuerda la
entrega
inmediata de
los terroristas**

Bruselas, 11 de octubre. La Eurocámara de la Unión Europea ha acordado la entrega inmediata de los terroristas que se encuentran en custodia en el Reino Unido y en el resto de Europa.

**El portavoz del
PP de Tarragona
era uno de los
objetivos de ETA**

El portavoz del PP de Tarragona, Juan Carlos García, ha sido uno de los objetivos de ETA. El grupo terrorista ha intentado asesinarlo en varias ocasiones.

**Telefónica
arrastra la boba
a un nuevo
mínimo anual**

Madrid, 11 de octubre. Telefónica ha arrastrado la boba a un nuevo mínimo anual. La compañía ha bajado su precio en un 10 por ciento.

Los científicos hallan residuos cancerígenos en el agua del grifo

► **Revelador estudio
del CSIC y del
Instituto Municipal
d'Investigació Mèdica**

► **El cloro genera una
sustancia de riesgo
al potabilizar el agua
contaminada de ríos**

► **El informe concluye
que causa 600 muertes
anuales en España
por cáncer de vejiga**

Madrid, 11 de octubre. Un estudio del Consejo Superior de Investigaciones Científicas (CSIC) y del Instituto Municipal d'Investigació Mèdica (IMM) ha revelado que el cloro, utilizado para potabilizar el agua de los ríos, genera una sustancia de riesgo al potabilizar el agua contaminada de ríos.



Pres. de España, José María Aznar, en un momento de la audiencia en el Tribunal Supremo.

**CIU replica
al PSC con
el aval del
PSOE a la
financiación**

Barcelona, 11 de octubre. La Ciutadella Republicana (CIU) ha replicado al PSC con el aval del PSOE a la financiación.

La Comisión Europea ha acordado la entrega inmediata de los terroristas que se encuentran en custodia en el Reino Unido y en el resto de Europa.

Zaplana excluye a los literatos catalanes de la escuela valenciana

Madrid, 11 de octubre. El ministro de Educación, José María Aznar, ha excluido a los literatos catalanes de la escuela valenciana.

14 October 2000.

El País

"No children ever stayed away", explained
Miriam Álvarez, manager of a nearby nursery.
"But we did turn off the water. It wasn't necessary,
but the parents asked and were worried".

cancer.” This alarming report, which raised a question mark over something as basic and essential as running water, did not produce any sort of dramatic response among the population. Apparently, with the exception of a few temporary reactions, society continued to drink from the public water supply as normal.

What phenomenon can explain the fact that this report did not create a situation of crisis in the public perception of the water supply? There are clearly two potential explanations: 1) society has its own systems for decoding the messages it receives from the media and is less easily influenced than first appears, or 2) the media (or some parts of it) have gone to such extremes of sensationalism or unfounded alarm that they have lost credibility. I leave you to consider the causes and consequences each of these explanations.

DEBATE

Vladimir de Semir. The two speakers have given an excellent and thought-provoking synthesis of the key issues in this debate. You will already be familiar with some of the points raised here, and indeed we have discussed many of them with each other. However, I hope that today's discussion will go beyond this, as we try to answer the questions raised by Gemma Revuelta, or any other questions which may arise. In particular, there is something which greatly concerns me and which I hope we will consider today. This is the selection of articles by the scientific journals themselves. Is a study into the "infidelity gene" really relevant? I give this example – in fact, it is one I raise often – because it relates to the real case of a study published in *Nature* which had an enormous impact in the media. Could it be that this article was selected over others in the light of its likely media impact? I believe that we are starting to analyze the role of scientific journals, their goals and how they operate.

Miquel Vilardell. Regarding the journals which send out press releases, and the question of who selects these, no article is sent out which hasn't passed through peer review. For example, a month ago *Medicina Clínica* started to send out a summary of all its articles once a month. *Medicina Clínica* releases a page listing all the original articles and their abstracts, and then one or two articles which the editorial committee thinks are probably the most important are sent out, and this is done by someone with expertise in the mass media. Presumably this is done in the belief that journalists do not have a scientific training; wrong, because Spain has such journalists and I guess they exist everywhere, but sometimes due to the fear that there are no scientific journalists who understand medical terminology, the information is translated and made easier to digest. The journals are also looking for a social impact, for the journal's name to appear in the newspapers. We all look at the *Quiral Report* at the end of the year, to see how many times we've been cited in the media. One assumes this is a question of publicity, finances, etc., and everything influences it.

Vladimir de Semir. But that undermines the review process undertaken by scientific journals. In other words, the scientific journal has fallen into the trap of saying, "Should I publish this because of the social impact it will have?"

Miquel Vilardell. No, no, no, I don't think so.

Andreu Segura. It certainly does, but that's hardly surprising, because it's not just journals but also research programmes which often try to have a social impact in the sense of influencing the community. Why are some problems investigated and not others? Well, among other reasons because it is possible to glimpse some benefit which may translate into prestige. We all have interests, and we're old enough to recognize that's nothing to be ashamed of. The problem is when interests are concealed, distorted and manipulated. And do journalists have interests, like researchers or industry? Well, of course.

Another issue is that the rules of the game have to be observed, and that we aren't misled. I am more concerned about the issue being presented as a story of goodies and baddies, although it is that too, because every profession has its crooks. But sometimes our interpretation of science is rather superficial. We have the idea that science reflects the truth and that strikes me as a bit extreme. Science is a human creation and shares the characteristics of lots of other things humans have created. So we should not use scientific "evidence" (which is an approximation of our knowledge of reality and a rational tool for understanding this reality) as a pretext for legitimating and imposing the values and interests of scientists.

While I was impressed by Dr. Vilardell's contribution, I don't understand his proposal for the position of a knowledge manager because, as he himself pointed out, this manager could also supplant the principal investigator in dealings with the media.

Finally, I was struck by the fact that Gemma Revuelta said that the consequences of the news reported in the media were not a matter for her. Well, she didn't literally say that they weren't a matter for her but, with due journalistic licence, this is my interpretation of her words. In fact, analyzing their consequences is one of the things which justify our presence here, and I am convinced that studying them is a good way of seeking to address the ethical issues raised by the media.

I am very grateful to Gemma Revuelta for her emphasis on public health because, despite its relative neglect within the health system, it receives far greater attention in the media. And not just because of the rare occasions on

which politicians have resigned due to public health problems, but also, above all, due to the major influence that the communication of these problems has on the health and well-being of people and populations. A current example comes from the threats to human health deriving from mad cow disease and, more specifically, the political, economic and social consequences of adopting drastic control measures, probably conditioned by social perceptions and errors in the public communication of risk: measures which may be out of proportion to events. If I tell you, and indeed it is well known, that the number of cases of iatrogenic Creutzfeldt-Jakob disease (that is, due to medical interventions) documented in the medical literature is over double the number of recorded cases of new variant CJD associated with bovine spongiform encephalopathy, I don't think anyone would dream of advising people not to go to the doctor. We should, then, address these issues both with great calm and with rigour.

Unfortunately, it is difficult to understand the meaning of probability, and risk is one example of this. Even health professionals find it difficult to fully understand what certain incidence statistics mean, for example. But the number of deaths from encephalopathy attributable to mad cow disease throughout the world is approximately the same as the number of deaths in Spain from traffic accidents each Easter. Every day, about a thousand people die in Spain but few people take this into account when assessing the importance of a specific health problem.

Óscar Vilarroya. I want to answer the questions raised by Gemma Revuelta because these are the ones I had in mind when I came here, because they strike me as fundamental. Starting with the second question [Is health information different?], I would say that it is, that health news is treated differently for a range of reasons. Some of these have already been identified, but I would like to focus on them in more detail. I refer to the interests which surround the person who transmits the news, and which correspond to the interests of pharmaceutical companies, the institutions which conduct research, the journals which publish the reports and need to make an impact, the researchers competing for funds, and citizens. Indeed, citizens, for example, increasingly view health not as a gift but as a right, and believe they have the right to demand information and to find a solution to their problems. Likewise, there are the

interests of the media owners, as mentioned by Vladimir de Semir in some of the articles provided as reference: those large groups which have a growing influence on what is said, how it is said, and how it should be reproduced in society. This dynamic, which no doubt is similar to other dynamics in other sections of the newspapers and other parts of the media, has a massive influence on how health information is treated and therefore merits a different treatment.

Regarding the third question raised by Gemma Revuelta [how is health reporting different?] there are several specific features which define health news. Firstly, there is a great deal of scientific and medical ignorance. What people know is much less than we think, although there is a positive counterpart to this, which is that people have much more common sense than we often assume; much more, and that's why people carry on drinking tap water. In this regard, I would refer you to a study by *The Lancet* analyzing the reaction of cancer patients to media reports of Di Bella's cancer therapy, published in Italy in 1998. And what struck me as positive, rather than negative as the researchers argued, was that only 50% of the sample had an increased expectation of being cured. At the same time, over 50% believed that, despite the opportunity offered by this new therapy, they should continue to pay attention to their own oncologists. And this among cancer patients, who are facing death. I was struck and surprised by the common sense shown by these people.

A second feature of health news is that journalists have a better scientific training, and scientists are more interested in society. And readers also take this into account.

A third characteristic which defines today's health news is what I'm afraid my professional background compels me to call the cognitive sphere of health information. I refer to the fact that the importance acquired by health and science information over the last twenty-five years goes beyond the "news values" to which Gemma Revuelta has referred, and is something new. Apart from the question of whether scientific news is innovative, is familiar, touches people's emotions, and is of personal relevance, science is beginning to offer answers to questions we have always asked ourselves. Let's consider the example raised by Vladimir de Semir in his paper: the woman who calls

a TV programme and says, “I don’t care what you’re talking about, but will this genome thing solve my daughter’s problem or not?” That’s the question, and this is the kind of question that science answers in ever greater detail. News can be news because it says something new. However, we should remember that people didn’t *want* to know that the Twin Towers had been destroyed. People didn’t *know* they needed to know it. By contrast, when it comes to health and science, people *do* know what they want to know. And what people want to know is often related to problems of science and health. And as science is beginning to answer these questions, the importance of health and science reporting increases. And being sensitive to this fact is important, because if we think that people are interested in health and science reports in the same way that they are interested in general news, then we are mistaken. People are far more interested in finding answers to their questions than in finding out what is happening in the world of science. And this confusion is where the problem of the transmission of health news is created, in its representation and recontextualization. To explain more clearly what I am talking about, I will use an analogy based on a headline in *La Vanguardia* which read: “World enters new era after finding map of human genome.” To interpret the value of this piece of news and the difficulty of transmitting it, I asked myself what would happen if, in the 1960s, headlines had been published saying “Novelist García Márquez invents fictional world which will change path of literature” or another saying “In his latest book Chomsky will change our centuries-old concept of language.” In other words, knowledge on its own is not information; something else is required. And this is why there is a difference between answering specific questions and, so to speak, simply providing knowledge.

I would like to end by commenting on the first question: whether health and medicine need a separate approach within the ethics of communication. In my opinion, ethics is almost a product, a consequence of a particular sort of human disposition. If a person is constitutionally unethical, I think it’s very difficult to put some drops in the water to make him ethical. That’s why I think ethics should be the result of creating better people, better journalists, better scientists, and by imposing external constraints on how scientific information is transmitted.

Xavier Carné. With reference to Óscar Vilarroya's remarks, I will stick to the sphere I am most familiar with: pharmacology, new medicinal products, and in particular their registration. I work with colleagues and we argue about whether this or that medicinal product should be released, and under what conditions. We have always argued that under some circumstances a medical item may not be news, and I'm going to explain what I mean.

I would divide medical knowledge into basic science and applied science. Basic science might be that a new protein has been found, which modifies X and this could be news, I won't get involved in that. In applied science there would be two spheres: diagnostic methods and therapeutic methods and medications. And in the world of medical news there would (simplifying greatly) be two aspects: positive ones (this medicine cures this illness or improves this condition); or negative ones (this medicine causes a disaster and must be withdrawn). However, it is impossible for there to actually be dramatic positive news about a medicine, and I'll explain why. You should never say "never", but I would say that it ought to be impossible for a report on progress regarding a medicine to appear on the front page of *La Vanguardia* or any newspaper. Why? Because progress, as we have often noted, occurs in small increments, with gradations, in sub-groups of the population, under particular circumstances, etc. The gradations are always so significant and the effects so relative that this is never new and innovative, and therefore not newsworthy enough to appear on the front page. I think that those of us who work in registration are often tempted to say to the journalists, let's come to an agreement and decide never to put anything about the benefits of any medication on the front page in the history of humanity, because it would be a lie. Not even Viagra is front-page news, because you have to explain who can take it, and Viagra has all the elements of scandal, the sex was important, but even with that Viagra shouldn't be on the front page.

Antoni Plasencia. Everyone here is very mindful of the concept of "ethics", even though we come from very different professional backgrounds. I think it is important, and this has been stressed here, to talk in terms of interest groups. It is good that we recognize this, and I believe it is the sign of a democratic society to recognize that information, including medical and health information, is an economic and social issue. From this ethical perspective, I don't know

exactly how each interest group has to deal with this situation and this recognition. But there is an element which I understand to be an ethical issue, and that is transparency, and some of these interest groups – in particular, the biomedical journals or some biomedical journals, I would say a growing number – are accepting and publicizing this. This is transparency regarding what they do, why they do it, and how they do it, and this relates to goals, processes, products etc.

So one of the issues for discussion is, firstly, what does “transparency” mean and how does each interest group define it and communicate it to the other interest groups? And the second issue is that each interest group shares aspects of this transparency with other groups. The biomedical journals – Miquel Vilardell referred to them earlier – constantly strive to explain, with varying success, what potential conflicts of interest may affect them, and to explain a range of aspects of the information they produce. I would say that some health authorities are also trying, with varying success, to ensure that part of what they communicate, part of their efforts, are based on transparency. This was the case of the Legionnaires’ outbreak in the La Barceloneta district of Barcelona. I was involved in this so I probably suffer from my own biases, but I think that it was actually an effort to ensure transparency which led to success. Without wanting to criticize, I think the media should also become involved in this effort to ensure greater transparency. We were talking about trihalomethane earlier, and the headline we saw was just one headline from three pages of headlines, with three pages each day and articles. I don’t know if the ordinary reader pays more attention to articles or headlines or what, but the focus of the article was very different to the contents of the newspaper. That makes me aware of the need to stress the importance of each interest group highlighting the issue of transparency around how and why it does things.

Jordi Camí. Right now I’m not too optimistic about achieving a formal ethics for media communication which accords with what I believe we understand that to be, such as stipulating a set of values and the rules of play. I’m not very optimistic, even though we need to really build it. There will be lots of factors and we will probably be involved in a long-running conflict between different interests, and this makes me very pessimistic about the chances of short-term success, and now I’ll try to explain why.

In this irreversible relationship between the media and biomedical journals, the biomedical journals exert an indirect influence on scientists and doctors. And now I would like to put to one side the world of media communication in the widest sense (the internet, the general population) and restrict myself to this relationship between the media and the biomedical journals. This relationship, I think, embodies the worst experiences of other situations and what's more I think it's very contradictory, because this transparency that Antonio Plasencia talked about, which we are calling for with regard to authors and their links with the health industry regarding the neutrality of the design of their experiments and opinions about their conclusions, in my opinion contradicts how relations with the media are organized, linked to selling more and having a growing influence. Of the tens of thousands of journals in existence, of the millions of studies published every month, there are eighteen journals which form the hard core, which wield the main influence and which have invented all these systems.

I'm not very optimistic because I think this relationship, which is irreversible, incorporates two sets of experiences which are already very complex themselves. One is the relationship between doctors and the pharmaceutical industry. This has been in existence for a long time; and is where our analysis of what conflicts of interest are comes from – not just ideological but also financial – and we've seen that it's a very complicated issue. This relationship means that the need to be honest about our research is heavily influenced by secondary interests such as financial ones.

But there is another experience which I believe this irreversible relationship between biomedical journals and the media also encompasses, and which I think is more important: the relationship between the political class and the media. I don't know much about this relationship but I know that today it is fundamental, and that politics doesn't work, cannot be understood, if not in relation to the media. I am not an expert in this field, but in the same way that, as Gemma Revuelta said, the shares in a pharmaceutical company may rise or fall depending on a news report, not in *La Vanguardia*, of course, but in the *New York Times*, so a politician's stock may rise or fall according to his reputation in the media. Just as what politicians are most interested in, apart from ensuring that nobody causes them problems, is

knowing how the press will react and how events will be portrayed in the media over the coming days, the same thing is happening in the world of biomedical journals and scientific lobbies. In other words, I think that a set of relationships is coming into existence which make it difficult to maintain objectivity, let alone independence. New perverse dependencies are being created, new relationships, and this at a time when, fortunately, educated society, or that sector which reads, increasingly demands the right to express its opinion, to participate; this is very relevant at a time when lots of sectors of society want to express their opinions. There is clearly a crisis of confidence, which I do not think is serious, between the world of science and society, medicine and society, at least in our society. So I doubt much progress will be made in the short term. I think it's very important that the different professional sectors have their own rules of conduct, which reflect their values, and which defend a particular ethical approach. I think this is the mechanism and, I repeat, I am concerned about what for me is the key relationship, between politicians and the media. We are already seeing that things are getting worse rather than better.

I'd like to end by commenting on the tap water example. I'm changing the subject a bit, but for me this is the paradigm, the example, and now Vladimir will listen to me too. Let's take it one by one, I don't think anything happens after a news report like, "Scientists find carcinogenic residues in tap water." Nothing happens after a front page like that for two reasons. Although I don't have any evidence for it, the first reason strikes me as being the fact that the front page of this newspaper already has very low credibility, and I am sure that the general media, who are fairly responsible, resent this. During the first 24 to 48 hours they do a very good job; it's a question of listening to radio programmes, opinion shapers on the radio, and at times like this they tend to inform themselves better, to examine the situation, to be advised by specialist, scientific journalists, and to rein in these alarming news items within a period of 24 to 48 hours. I remember a piece published in the *Eco* newspaper, which read "Pollution kills". We need to treat this as an example, and we should discuss it, and I think that, as Toni Plasencia so rightly said, this work has to be followed up with an article and two or three days later, because I think it's a block, it can't be ignored.

And I repeat that I'm pessimistic and now I'll explain my understanding, based on similar information to what NATO appears to have about Bin Laden but can't reveal, of this tap water issue, because this was a story by a respected journalist, who became engrossed in an anecdote and, without realizing it, was exploited by a range of influential economic power centres. Meanwhile, the scientists, the media owners, and people responsible for generating news failed dramatically to sort out this mess that fortunately only lasted four days.

Over a year ago, and the scientist considered that the information was for domestic Spanish consumption, not of international relevance, *Medicina Clínica* published a study which was of sufficient importance for the Municipal Institute for Public Health to hold a public debate about what would happen when these products are classified as products, making sure that there aren't so many, etc. This event, which took place over a year ago, was attended by journalists. Some of them explained this to the speaker; four months before he was already running around the Municipal Institute for Medical Research arguing with the researcher about a piece of information he was obsessed with. He explained it to the company, and they asked him to study it in more detail but they would decide when this issue would be made public. He got an order from the central committee at the end of the summer: that the content of the information urgently had to be changed. The researcher, I think he had the bad luck of wording one sentence badly, just one sentence, which said that these trihalomethanes are involved in, could explain, could have something to do with, are on the list of risk factors probably associated with 20% of bladder cancer cases in Catalonia, and this 20% is 600 people. That is where the journalist became obsessed with the anecdotal, and the scientist didn't know how to get beyond the 600 deaths, because there was another headline, "Tap water causes 600 deaths a year." This is what journalists exist for. The reality is that, from the information we have, as this went in parallel with a demonstration that the water company, which I won't name, purified very well, worked very well, and did a very good job. Then we found that it was very good for the company, which had nothing to do with the media, probably in agreement with the water board, for this piece of news to come out in the way it came out in order to start creating the background for a future rise in water prices based on the need to optimize purification. That's the paradigm. It's the same, you may not

believe me, but the local council held an emergency meeting and someone thought that this was related to the campaign to divert water from the River Ebro. Nothing of all that; water prices. But I think that's the paradigm of why I'm not too optimistic about building an ethics of medical communication as such in the formal sense, and I think that instead we need to follow different routes.

Francesc González Ledesma. I'm learning a great deal today. Most of you are medical specialists or have senior positions in scientific journals which are beyond me, but I'd like to speak as a street-level journalist, that is at the level of the user and the audience of medical news. I believe that, as the chart shows, medical news is gaining in importance and this is primarily because people see health care as a right, not a gift from the state, and because medical news is of growing interest to people who are ill. Because ill people are basically looking for one thing – for hope – and any news which gives them a glimmer of hope is very important to them. I was particularly interested in what Gemma Revuelta said about the report in the *New York Times* which I suspect was written in bad faith, because the word “mice”, which appears at the end, should have been mentioned at the start, and maybe there were economic interests behind it.

I believe that absolutely any news item can give rise to false hopes and above all if there is an economic interest behind it, then that's very dangerous, and journalistic ethics has a big role. I would like to tell you a bit about the process news goes through before reaching the audience. Normally, when a piece of scientific news reaches a newspaper, the first problem is the lack of specialization of the writer. Vladi, if I can call him that, because we've worked together for many years and wherever he works that's how he's known, has told us about the training going on in the area of scientific journalism. I think this is very worthwhile, there's a real need for it, but just now when scientific news reaches the papers it is received by someone who generally doesn't have much of a background, and this makes the process of evaluating it a bit risky.

The second issue is urgency. In the media things are often done in a rush, that's not just a stereotype. Anyone who has worked for a newspaper knows that when the time comes to close the day's edition people's attitudes change;

orders are more peremptory and as a result there is less reflection. I've been through very stressful situations when the senior editor has said it's time to close, and each time he says it a bit louder until by the end he is foaming at the mouth. Well, when that happens, reflection is just about the last thing on your mind, and you end up saying, well, it's time to close the edition and what the hell is happening with that cancer piece? As a result the writer doesn't have much opportunity to reflect on the piece, and is likely to just hand it straight over so it can go in. That's the first danger, and I think it's pretty much inevitable.

Then there's the fact that newspapers are looking for – and we have already seen some examples – headlines that really grab the attention, that pull readers in. Obviously all the headlines we've seen had a big impact on the public, but their scientific content was questionable. If a newspaper, for example, reaches the conclusion that sexual activity may improve or help to cure cancer, there's no doubt this would be interesting to a lot of people, but actually it would be nothing more than an attempt to grab the public's attention. We've talked today of the need for an ethics of journalism. And the instrument of this ethics is the Information Council of Catalonia, of which I am currently president. One of the things I'd like to say here – and I'd be very happy if this happened – is that although the Information Council of Catalonia does not have and does not want to have any power to impose penalties, we would like to be able to force newspapers to publish corrections. Because, for example, an inaccurate piece on cancer or on the quality of drinking water can cause great public and social alarm, and it should therefore be corrected. I really hope this can happen.

And I would also like to clarify a bit. There are two types of scientific news. There is news which doesn't affect public health because it relates to science itself, over the long term, and as a result I believe that there is little need for rectification. I recall an anecdote about a gentleman, a geologist, who said, talking about an era of the earth, "about 4 or 5 million years ago ..." and a listener said, "that's right." When you're talking about something like that, from millions of years ago, there is no need for correction. But when you're talking about a news item which says that we can cure illnesses which are very common or have many sufferers, I think we do have to issue a correction, that's something I'd insist on.

I would also like to bring up something which may be helpful. The Department of Health of the Region of Catalonia brings together a group of individuals belonging to a range of professions, all sorts of people, perhaps inspired by the North American doctrine that large administrative bodies should include the lift attendant, the receptionist, etc. because sometimes they are aware of problems which scientists haven't noticed. A range of people get together to share their ideas about public health. And one of the proposals which has been made there – I would also like this to be adopted – is that the Catalan health authorities, not the politicians because politicians tend to say everything's fine, but the health authorities of Catalonia, should hold regular press conferences which would be attended by journalists and would address the big issues. For example, nothing more has been said about mad cow disease, there's still a tremendous amount of uncertainty, nothing more has been said about Legionnaires' disease; we don't know what exactly could happen. Nothing more has been said about the curative powers which could come from study of the human genome. It would be very good if journalists had to attend a press conference organized by scientists, and they would no doubt report it because although the press itself may not be wise it can transmit the voice of the wise.

Victoria Camps. I would like to return to the question raised by Gemma Revuelta as to whether there is a specific ethics of the science of medical communication, which I think is a very big question. When I heard it, first of all I would have said not, that ethics is for everyone, and that there is no specific ethics of anything.

As Óscar Vilarroya said, I don't believe that ethics is like a pill we can put in the water and which changes our attitude, but rather that it consists of asking what it means to be a good professional; how a person should exercise their profession. And this brings us to a much wider area of analysis, to things which I believe could at least make us more aware of what needs to be improved.

In the first place, is there a specific ethics of medical communication? Perhaps we should ask ourselves the more specific question of whether we are using and understanding the word "inform" properly. I believe the way we understand it is very simple. Many philosophers of language have spoken

about what are called “linguistic acts” and they say that when we act linguistically, that is, when we inform people, for example, what we have to look at is the intention with which we do this. Our intention regarding the audience is significant. Information is not always aimed at the same type of person. Following this idea, I believe that medical communication, not scientific communication in general, but medical communication, should have a specific intention, because it is aimed at the majority of the public in a very particular way. It’s a bit like talking about the ethics of communication aimed at children on TV, for example. Why does it concern us more than other types of communication? Because it is aimed at an audience which is more fragile, more vulnerable, weaker, and which needs to be educated.

So, when analyzing information, it is worth considering the intention behind providing the information; this is not always the same, and indeed there may be a range of different subsidiary intentions rather than just one single intention. In this regard I would like to raise another issue. I don’t know who said that we should magnify the idea of truth, which relates to information and the ethical codes of communication and journalism. We believe that a test of whether information is good is whether it can be verified; in other words, information which reports on facts which are correct. Xavier Carné said a moment ago that we can’t provide news because there is no news which is completely true; but there are always gradations, there are always things which go unsaid, there is no such thing as “true” information.

But why don’t we ask another question? Information about delicate or sensitive issues should be instructional. This notion is one which journalists find scary, because we live in a world of experts where everybody has their own function, and education is supposed to be the function of teachers, of professors, of parents, but not of the rest of society. However, the communication process in general, and information in particular, can instruct or mislead people. I believe that the aim and intention of instructing people, particularly in delicate issues which greatly affect them, is more important than the question of whether the information is true or not. Because it will never be completely true, information can never be fully and absolutely verifiable, but we do have to think about whether it is instructing or misleading the public.

There is another issue which I think is also ethically important and which has already been discussed: the issue of news which creates social alarm and contradicts other values, such as transparency. It goes without saying that the public has the right to be informed, but there are ways of providing information which are counterproductive and create alarm. It is counterproductive to identify dangers or problems for which there is no solution.

I would like to end by discussing the implicit aim of the information. Here we have talked about waiting lists and heart patients. What was the intention of the news? Revealing the existence of a problem of deaths due to waiting lists, or simply protesting at an unsatisfactory situation regarding the provision of care? I think we must ask to what degree any method serves to achieve a particular goal. That is also an ethical question.

And finally there is another issue regarding credibility. The credibility of the media has been considered in terms of the impact it seeks, and this impact often undermines its credibility. Social impact, economic impact, conflicts of interest; all this goes against credibility. Here I believe we have to be very honest and ask whether credibility is really a priority. Is the media concerned with credibility? Or are economic or political interests more important than credibility? It is true that people have much more common sense than we think; it is true that the reading public are educated, and that educated people are more critical and more questioning. What happens with advertising can also happen to the media in general; advertising does not just inform, advertising has another objective, which is to persuade, to convince, to sell a product. Nobody believes adverts, of course. Their intention is not to tell the truth, but to sell. Should that be the aim of information, and will communication ultimately lose credibility because other interests are stronger?

Ramon Bayés. The issue which concerns us here is a complex one, and the speakers and other contributors have raised a lot of points to consider, all of which makes it difficult to follow the thread of the debate, to provide answers and raise questions which can clarify the many problems we have identified. What I want to do is briefly comment on some aspects which have particularly interested me.

I will start with something mentioned by Miquel Vilardell at the start of his contribution: the ethical principle of non-maleficence. As he suggested, I believe that this offers a common starting point for health professionals and journalists. Do journalists ask how to communicate information in a non-maleficent manner; that is, in a way which does not harm, or does as little harm as possible to, the audience at which it is aimed? In news items which may have an emotional impact on a lot of people – cancer and Alzheimer patients, people infected with HIV, etc. – to what degree are some journalists aware of the negative impact which information which has not been properly checked or a sensationalist headline can have on readers, listeners or viewers? If journalists became more generally aware of the principle of non-maleficence, if it became a habit among them, this would definitely bring benefits for the mental health of the population. The cost in human suffering of a false, inaccurate or distorted image on the seriously ill can be enormous. I believe that this issue also relates directly to the contributions of Francesc González and Victoria Camps.

Another point I would like to mention relates to the communication process itself. What is sent is one thing, and what is received is another, and it may be the latter which is really important. Perhaps we need an observatory not just of what is said but another one to monitor what the public understands. This would require a network of users representing the general population, or, at least, a network of experts, who could be consulted with regard to news items, perhaps by email, immediately.

Vladimir de Semir, for his part, has talked about “fast thinking”. I believe that technological progress is making this phenomenon increasingly pervasive. The danger from a psychological viewpoint is significant, because it has a very dramatic impact on human behaviour by reducing the amount of time available for reflection and for exercising freedom of choice.

Another issue which occurs to me regarding what Gemma Revuelta said about the story in the *New York Times* is that we talked about the credibility of this source. In this regard, it would be interesting to know whether the journalist or the people who knew that the newspaper was going to publish the report bought shares in the pharmaceutical company the day before. In this case, it

would be a clear instance of the misuse of privileged information and of professional malpractice.

Jordi Camí has also mentioned another type of pressure, that of big political interests. And in this regard I think that, sometimes, the size of the trees appearing in the media stops us from seeing the wood we are interested in. A specific example which has had a major impact in the media and on the public is the plan to divert water from the Ebro river in northern Spain. When comparing the pros and cons of this plan with the option of bringing water from the Rhone to supply the city of Barcelona, people have spoken of flows, of costs, of possible environmental damage etc. But, as far as I am aware, there has been little or no discussion of the quality of the water which either plan would leave the inhabitants of Barcelona drinking in the future. Some years ago I was told that the waters of the Rhone were very polluted by heavy metals and by mercury in particular. Is this true? Why, in a public project of this scale and importance, and given that politicians won't do it, do journalists not treat the possible medium and long-term effects on the health of consumers as being of prime importance?

Finally, within the field of communication there are two levels. One is the transmission of information which, by its very nature, has to be treated urgently and which is therefore very difficult to verify. It may be that in the field of health this is rare. The second level relates to those situations where the journalist has time to reflect, review, check his information and ask experts for a detailed opinion. If this time exists but is not used properly, in my opinion there is a clear ethical transgression.

Dulce de Fuenmayor. It is an honour to have been invited to participate in this debate, and as a nurse I will seek to represent patients and service users to some degree. Gemma Revuelta has drawn a fairly clear distinction between scientific and social communication. I think this division is very important in this debate, because we need to analyze them separately, what is the ethical content of scientific communication, and what interests are operating within this field, which is very specific to the world of science, to the scientific world, which is more or less a closed field; and social communication in relation to science, and the links which arise between science and the media.

Regarding social communication, which is what interests me as a representative of service users, there are some factors which distort this communication. I would start by saying that one of these is particularly important: in an advanced, developed society such as ours, a European welfare society, western society in general. We are very preoccupied with health, perhaps because the lower levels of Maslow's pyramid of needs have already been achieved, the most basic needs are covered and we therefore begin to demand more from our environment and our society, and this preoccupation with health is typical of advanced societies. People in underdeveloped countries are never preoccupied with their health, and this may strike us as curious. They're in a really bad situation, they don't have anything, and as a result their health is very poor, but it is far from being their main concern, because their main concern is surviving, having water, if the water is drinkable then even better, but at least water, having something to eat even if it's just enough to get them through the next 24 hours.

Although this preoccupation with health is typical of advanced societies, it is not accompanied by greater knowledge by these members of society regarding the thing they are concerned about, in other words, there is not a greater knowledge on the part of the population regarding health problems and possible solutions, but rather there is a degree of ignorance and they are therefore receiving information from the general media which is often biased, not from scientific media because at the moment this is not sold through newsagents (although some newsagents are now trying to sell some specialist publications). So it's strange that the media, which is really the point of communication between the "ignorant" user and the health world, has not paid adequate attention to training the journalists who will have the job of transmitting this knowledge. This is an issue which has already been discussed here, and could be one of the goals to be taken up by this discussion, the need to train people, because we cannot accept that the journalist who will transmit this knowledge to the population should fit the sensationalist profile, but rather that of the rigorous reporter who is always mindful of the nature of the reader he or she is addressing.

Then there is also the question of how the news is presented. I don't know exactly how newspapers work, but I guess someone is responsible for setting

them out, and deciding what the headline will be. We have to recognize that a lot of people just look at the headlines; they don't read the reports. Nowadays there are papers which are given out free in the street, which provide a quick summary of the news, and I think that's good because it keeps people informed. People who don't read much get the news, a quick preview of events. Lots of people don't buy a paper but just read the headlines, and even those who do buy one don't necessarily get past the headlines. So what happens? Well, often the headline has nothing to do with the article. When you read the article, its contents are completely different from the headline, or what you think the headline is saying; you understand in good faith something which it doesn't actually say. When it says they've cured cancer and then the report talks about experiments with mice, then if you haven't read the article what sticks with you is that they've found a cure for cancer. Newspaper headlines are mis-used like this, and that's logical in a competitive world like the press, because headlines are what sell. If we are talking about the ethics of the media, the ethics of scientific groups, medical ethics in scientific publications, then we need to talk about the ethics in general of all the groups involved in transmitting scientific news to people who are concerned with their health.

Maria Casado. I found the two opening contributions very interesting (and complementary, which is ideal) and I would like to comment on both of them. In fact, the million dollar question is the one raised by Gemma Revuelta: is there a specific ethics of medical communication? My answer is the opposite of that offered by my colleague Victoria Camps, in the sense that I believe there should be, because there are specific conflicts of interest, and these arise, what is more, in a specific context where, in my opinion, an applied professional ethics is required for all of those operating in this field. Other than that, I agree with Victoria.

The transmission of medical knowledge can occur in a range of contexts, as we have seen. If we refer to the field of science and the relationships between scientists, then scientific journals are the main medium of communication; but if we refer to the scientific communication which occurs in the newspapers, we have to look at the issues from a different point of view and, to a greater degree still if we refer to the information which appears in the audiovisual media, varied and excellent as it often is. All of this comes within the scope of the issues

we are considering here today, and what distinguishes this is that it brings the general public into the debate – or a part of it, at least – and this less educated sector will sooner or later be the beneficiary of the scientific advances whose communication we are discussing.

This is why I believe there is a specific responsibility and certain factors should be borne in mind. The first of these, as has been mentioned, is the vulnerability of many of the recipients of this communication. This is obviously different to the vulnerability of what are usually termed “vulnerable groups”, but it nevertheless exists as soon as medical communication generates hopes which are often doomed to be disappointed, because there is a long gap between the initial scientific discovery and its clinical application (some, not without reason, have compared this medical information to the financial futures markets). This is something we have to take into account.

At the same time, and let’s be frank about this, the field we are discussing involves money, lots of money. There is so much money allocated to health spending, and the interests are so big that the conflicts can be enormous, and sometimes these are far from explicit.

Perhaps one of the aspects most closely related to the ethics of communication is the educational aspect, and in the field of medical communication particular attention must be paid to this. I don’t think we should take as our point of reference the idealized image of the journalist transmitting knowledge as a member of a disinterested fourth estate, because the reality is that newspaper companies are just that: companies whose legitimate aim in a market society such as ours is to make money. This reality completely changes the rules of the game with regard to the notion of the purpose of the press which continues to exist in the collective consciousness. And that is how my question relates to Gemma Revuelta’s million dollar question: and it relates to whether we need to make explicit what we seek to achieve with this communication. In other words, why we are doing it, and what for, given that this aim will clearly influence how we do it. What are we trying to do: disseminate information for the public, or talk to our colleagues? And this involves a real difficulty, because anyone who sits down to write something, for a newspaper for example, at least anyone who is not a journalist by profession, when that person sits down in

front of the computer the first thing he has to ask himself is whether he is writing for his peers or for the rest of the population. I think that's something we have to think about.

At the same time, with regard to the classic issues of the ethics of communication in any type of news item, I believe that the traditional questions continue to be valid, as we have seen with issues such as water, grapes and many others. How do we select the item? How do we check the credibility of the source? How do we follow up the report? These are issues which strike me as fundamental. If the item has not had any impact on the population this may be for a range of reasons which do not necessarily relate to the credibility of the medium but may concern what has happened regarding the other participants in the process: how politicians have responded, what scientists have said, what other elements have been involved. I think all of this can have a significant impact.

I'd like to finish by referring to an issue raised by Miquel Vilardell, something which Oscar Vilarroya and Toni Plasencia have already referred to but which I would also like to highlight, regarding science and truth. Those of us who are not experimental scientists tend to feel that, however empirical and verifiable scientific truth may be, we must remember that it only provides an explanation of one part of an increasingly fragmented reality, and that it cannot explain everything. These individual explanations may be as verifiable and true as one could wish for, but they do not provide understanding if we don't place them in context and link them up with the rest of our shared knowledge, otherwise we are left with the sensation of being confronted with an "untrue truth" as Xavier Carné said. We therefore need to create spaces for shared reflection, what some anthropologists have termed co-laboratories, because there is an ever greater need for them, and the way the major ethics committees operate may be illustrative in this regard.

Àngels Gallardo. María Casado has already begun to open up an idea which I wanted to raise, which I share with her. All of us will have to find some way of establishing the rules to govern a phenomenon which involves us all. If we don't impose our rules, then ordinary people will do it for us. An example is the tap water case discussed earlier. Regarding the ethical intention of the

people who write in the media, personally I think that the only possible intention is that of being of some help to the people who read the information, helping them, relieving them or however. That's my personal opinion.

First, I would like to comment on something which Jordi Camí said regarding the relationship between the mass media and scientific journals. I think that rather than a relationship of equals, very often we find ourselves in a dictatorship and that sometimes we're almost forced to publish news because this journal has published it and sometimes that helps sales but very often it's a kind of obligation to publish just because it's what a particular journal has said. I think it's another pyramid-shaped phenomenon, and at the very top is the pharmaceutical industry, which is a very powerful industry which right now is really influential in the areas we're discussing. I think that if over the last three years the interesting health news has doubled in the mass media it's not because twice as many diseases are being cured or because twice as much is known about these disease, or even because people are twice as interested in their health, because as far as I know people have always been interested in their health (however much information you provide, it's one of the subjects people have been most interested in for the last 3 years and for the last 15 years). The only new phenomenon is the appearance of more and more companies dedicated to releasing health information promoted one hundred per cent of the time by pharmaceutical laboratories which generate interest in a disease and then two months later announce a new drug as if it was really a cure, referring to what Xavier Carné said earlier. So they're generating interest, desire, the need for health information; first of all they generate the interest, and then the information. So the role of the general media, very often, and I'm talking on behalf of my colleagues or at least some of them, their role rather than disseminating is to restrain, to channel, to filter, to somehow survive a daily bombardment of reports which leaves you doubting all of them and, if you can, you don't publish any of them. That's the reality and it involves all of us.

I really enjoy these discussions which are normally between colleagues who all know what each other thinks, more or less, but I think it would be good if this message could come out of our discussion, above all what Dr. Vilardell and various others have said, affecting both the directors of the media and the pub-

lic, that we should be a bit more critical, in particular of the non-written media because in the written media there is still a degree of control but in the audiovisual media, the immediacy the superficiality imposed by the lack of time for information, and their impact, all of this is multiplied by a thousand.

Josep Lluís Segú. First of all I'd like to say thanks for inviting me to take part in this forum on the issue of the ethics of scientific communication, which is of such importance to the daily work of an editor specializing in health. My job is to defend the role of the editor of *Medicina Clínica*, as the person who is responsible for the economic viability of the publication, rather than its scientific and editorial management, which corresponds to Dr. Miquel Vilardell.

In this regard, I would like to stress that the editor's main concern is to satisfy the reader. Producing a publication which is of interest to the group at which it is aimed is the key to publishing and to its financial viability. For a scientific publication to be of interest to its readers, it must be innovative, interesting and accurate. To this we can add that the publication will have a particular editorial line and should be designed in a way which encourages people to read it. The skill of the editor of the journal consists in publishing articles which meet these characteristics to the greatest possible degree. As I see it, it is the question of accuracy which has the greatest ethical component, given that the publication is aimed at professionals who are already well placed to judge whether it is innovative and interesting.

The accuracy of a biomedical article can be analyzed from a range of viewpoints. These range from methodological issues, regarding the design used to obtain the results of a given study, to analysis of the interests of the authors and sponsors of a particular article, what we refer to as conflicts of interest. When analyzing the methodology used by the authors of articles from an ethical perspective, the editor and reviewers work on the basis of good faith in the authors. They assume that the author has not submitted false or manipulated results for publication. They assume it because they really believe it, but also because they do not have any way of checking the accuracy of the information appearing in the manuscript. The peer review process which the manuscript undergoes to decide upon publication only indirectly allows the detection of inaccuracies, errors or issues which are not clearly explained which could lead

to the results being inaccurate. However, the editor is not responsible for systematically checking all the data included in manuscripts.

Another issue relating to the good faith of the authors concerns analysis of the conflict of interests. In this context we could define a conflict of interests as those results or conclusions of an investigation which might favour a particular group or company in which any of the authors have an interest. In biomedical research there are many possible sources of conflicts of interest. This may be not just financial but also political or professional. Such conflicts are often subtle, and frequently escape detection by editors and reviewers. In this regard, the strategy adopted by many leading biomedical publications to protect their readers from a possible lack of independence in particular articles as a result of the interests of authors is to promote transparency. In other words, these publications require the authors of articles to explicitly state whether there may be conflicts of interest relating to the article submitted for publication, and if so then this must be stated explicitly before a manuscript is accepted. This policy is intended to give the reader the opportunity to identify the author's interests so as to judge whether these may have influenced the results being presented. *Medicina Clínica* plans to adopt this policy in the near future.

Some international publications such as the *New England Journal of Medicine* go even further and do not commission any contributions (reviews or special articles) from authors who have revealed interests in the issue being analyzed during the two years prior to publication and who do not undertake not to have such interests in the two following years. While this strategy is clearly good for the neutrality of the publication, at times it can make it difficult to find prestigious authors in certain fields of medicine, as the best authors are those who are involved in the greatest number of projects and, as a result, have the widest range of interests.

Another potential source of ethical conflicts in a biomedical publication comes from its financial model. The business model of the majority of these publications, including *Medicina Clínica*, is based primarily on advertising. In this regard, the advertiser may be inclined to influence the editorial content of the publication, especially regarding those issues which could harm its economic interests. When these conflicts arise, it is the responsibility of the owner

of the journal, whether this is a scientific society or a publishing company, to maintain the editor's independence regarding the contents of the publication. In practice, and in our context, I should say that such cases have arisen only very rarely and our strategy has always been to support the decisions taken by the editor of the publication.

A second issue I would like to address relates to the consequences, in terms of health outcomes, of information about health which appears in the mass media and on the internet. I confess my ignorance in this area, but I have the impression that to date there is no evidence of potential health problems resulting from information appearing in the media, even if this is imprecise and often difficult for the reader to evaluate. In the specific case of the internet, the large amount of unverified health-related information has often been blamed for the potential problem of people with illnesses following inappropriate or misleading recommendations. Special emphasis has been placed on medical second opinions on the net. I would like to know if any member of the panel has information regarding this issue, as my first impression based on the scant information I have been able to review, is that until now no major problems of morbimortality are associated with imprecise information appearing in the media.

Jaume Guillaumet. I will talk as a journalist, but from the specific perspective of journalist training, and the analysis of journalism, which is the job of universities. I will make three comments and will try to keep it brief, and if anything is unclear I will be able to clarify it this afternoon. The first regards front pages, the second relates to the place of science and medicine in the media, and the third concerns the ethics of medical communication and of communication in general.

Firstly, regarding front pages, I would say that we don't have front pages any more, we have shop windows. According to classical journalism theory, for informative-interpretative newspapers the front page is a space where, according to a hierarchy of columns and font sizes, the news is presented depending on its importance, so that only very rarely does the front page carry a news item taking up five columns in 72-point font or even larger. And according to the same theory, the typical sensationalist popular daily newspaper is precise-

ly the paper which has the largest headlines possible and the most spectacular photographs it can find to grab people's attention. Now, if you think carefully and recall some of the front pages presented by Gemma Revuelta, the three daily newspapers published in Barcelona by locally-based companies have front pages of the second type, even though they are not sensationalist but are, rather, serious, informative and interpretative newspapers. Of the three other newspapers published in Barcelona as local editions of Madrid-based publications, two retain the classic front page format based on columns etc.

So, if there is no front page this means there is no news, and in any event if there are no front pages this is because the front page is provided by the radio and TV news. If you think for a moment, you'll realize that actually TV news programmes do have a front page. There is a series of headlines at the start which makes it absolutely clear, following a hierarchy of order and space, which items are most important, and even on the radio this hierarchy is crystal-clear, to the point where on the non-stop news channels there are three permanent news items, which are the most important ones. So, if the city of Barcelona didn't grind to a halt on the day when the front page of a respected newspaper reported that tap water could cause cancer, that was because apart from this front page, the news didn't appear on the other front pages, or not with enough prominence. My impression is that this report was not sufficiently credible to appear in the other papers, or to be discussed the next day, and above all to feature on radio and TV reports which would alarm people and create huge crowds looking for water wherever they could find it. So there aren't any front pages. Another point, as we have seen in Gemma Revuelta's presentation, is that the newspapers allow us to analyze media communication, scientific communication. However, for the purposes of public health, what really matter are TV and radio headlines.

Secondly, regarding science and medicine in the media, I believe the question was whether scientific and medical communication require special ethical treatment. My reply is yes, of course they do, not just special treatment but preferential treatment. I'm sure the information shown in the graph, this multiplication by two, in just three years, of the amount of space dedicated to medical information is very significant, but I get the impression that if a subject area has grown and is on its way to dominating the media in the future, this is

the one, because it relates to our well-being, to life. And although we live in a very technological society, with big scientific advances, it is also true that these scientific and technical advances generate threats. It seems strange to say that tap water might cause cancer, but it is also a potential hypothesis.

Allow me to make an observation. The media talk about what society wants it to talk about; there are no fixed categories. As a result, they will talk increasingly about medicine and science because that is what society wants. The media has already done that, but in the past it discussed emergencies or provided specialist comment, but even when talking of emergencies I like to recommend a glance at the past to see how the Barcelona newspapers of the second half of 1821 treated the yellow fever outbreak which killed over 6,000 people in the city that year. Even today I am envious of how the *Diario de Barcelona* treated the participation of the city's doctors, with very detailed information. However, it is true that journalistic standards have been set from the beginning by political and cultural information. More recently, at the start of the 20th century, sports reporting provided another set of standards which often mixes with and contaminates the others, and more recently still economic news has had a major influence.

As a result, I hope that medical and scientific information will also have an influence on journalistic norms, because one very important thing which goes against traditional journalism is the need for positive information. In the classical rules of journalism, there is no place for positive information; these rules are established, to use a legal metaphor, by case law, by precedent, but in journalism good news is not normally news. The fact that, in the sphere we are discussing, positive information is a principle gives me a degree of hope that it may be included.

And thirdly and finally, to place the issues at another level, rather than saying whether it makes sense to talk of ethics or not, because I believe that despite everything we would all more or less agree, I think it makes more sense to talk of professional principles than of ethics. I think that sometimes we talk about ethics but we're not talking about ethics. Often when we talk about ethics we should be talking about professional principles. And I say that because we're going through a special situation, and this debate about the rise of medical and

scientific information and its increased inclusion in the media occurs at one of the most critical moments in the history of journalism and social communication. I don't know whether to call it a situation of crisis or a situation of change: if we use words properly then it's the same, it means a crisis or a transformation. But, well, we've seen examples from what is generally called popular journalism. But journalism just now, even in the pages of leading newspapers and on TV reports, has moved a long way from what used to be of public interest, it's gone a very long way and addresses lots of other things which aren't strictly in the public interest. Even within the field of topics of public interest, there has been a phenomenon which just about everyone has mentioned and, particularly at the start, the chair and the speakers, which is what would be called information saturation or over-information.

This gives rise to a number of things: it blurs professional principles, and makes it difficult for journalists to know how to use their traditional tools in the face of completely new situations which sweep everyone along. The old situation which Francesc González Ledesma referred to, of the chief editor of *La Vanguardia* foaming at the mouth, no longer exists, and instead a thousand news items come in every day, and the problem is which ones to choose, which ones to believe or not, but knowing that in the end you have to publish one or the other. This blurs professional principles, but it also reduces the impact of the information process. This is the source of great difficulty for journalists, because it means they are being converted into mere transmitters with very little decision-making capacity. The journalist becomes little more than an operative, an information clerk. In this regard, I think – and I know this is very easy to say – we should argue that the journalist should be responsible for selecting and interpreting, not for giving the public 10 grammes to make a kilo with a lot of other things, but giving him 1 kilo, selecting, screening, weighing, not bombarding the public with news every day, but providing a summary. That's very difficult, and I don't want people to take it as a compliment because it isn't, but I believe that the principles of medical and scientific communication outlined by Dr. Vilardell are relevant to the difficulties we are facing in this moment of crisis for journalism.

Gemma Revuelta. I just wanted to clarify something which came up at the start of the discussion. Andreu Segura claimed I had said I was not concerned

with identifying the impact of the media on society. I hope he just misheard me, because this is precisely the issue I believe to be most interesting. We spend our lives taking decisions; in press offices, in the media, as journalists, in politics etc. We take decisions about the information we have to give, and we think about the impact it will have. “This will cause a scandal, people will be alarmed, they’ll get frightened.” Or the opposite: “We’ll give this information because then people will start to use olive oil.” We take lots of decisions, and we very rarely have a scientific basis for this, and today provides a good opportunity to discuss this issue. We don’t have much scientific basis for predicting the actual impact of information and how it is provided. So I suppose that in this case it’s not that it’s not my responsibility, but rather that I, in all modesty, consider that I lack either the professional competence or the necessary information. And this information is not easy to gather, involving as it does both communication science, where there have been very interesting studies of how information is received, and social psychology, which has analyzed in greater detail the consequences of a particular piece of information, how it can modify an attitude or a pattern of behaviour. In other words, this is such a fascinating field of science – and I think we would all like to know more about it in order to monitor the work we do every day – that it is obviously of concern to all of us.

Cèlia Ribera. I have found the whole first part of this debate very interesting because I have learnt a great deal, thanks in particular to the speakers and also to the rest of the participants. The discussion was very enlightening. I’m not going to make any grand or dramatic statements. I would just like to raise some issues which have been omitted, and which may strike people as obvious but which I think we need to take note of. For example, when people have referred to the significant increase in the number of newspaper pages dedicated to health issues and we have also discussed the possible decline in the impact of the information – an issue I will not go into here – what I think has not been mentioned is whether this increase in the volume of information has been delivered using the same resources which were available a few years ago: that is, without providing more staff to deal with this new flow of information. Everything would indicate that there has not been an increase in staff.

Although I am not currently involved with the general press except on an occasional basis, but rather with the specialized press, I would like to highlight

another of the weaknesses which I see in the general media, with a few notable exceptions. It should be clear that health information cannot be dealt with in the media in the same way as any other kind of news, and that there is an obvious need for greater specialization when tackling scientific issues. While some sections of the papers – for example, the economy and sport, to mention a couple which are accorded great importance – have specific journalists dedicated to covering them who have specialized in the subject area concerned (through studies, years of experience etc.), by contrast the health section tends to be a bit of a mixed bag, whose journalists soon move on. This morning we have had the example of Àngels Gallardo, a highly respected journalist who works in this area and takes a very thorough approach to the news. But this is not typical of most newspapers, where health is part of the society section, and the way jobs change within the media means that any journalist can end up in the society section, and the last one to join ends up dealing with health. This obviously doesn't help to ensure that the health section is well regarded within the media, either internally or externally by the reading public.

Regarding other issues, when discussing whether we need a special ethics for health information, that also depends. As has been said, there are conflicting opinions. Personally, I think we need a personal ethics, and the rest then follows. There are different ways of tackling health information. Here we have been talking, for example, about scientific journals, the leading journals and the general press. Well, there are also journals such as *JANO*, which is aimed mainly at primary care doctors, and has both scientific content (medical and healthcare) and a cultural section. Addressing doctors is very different from addressing the rest of the population. When you've done both, when you've worked in the general press and spent years working on a radio programme dedicated to the world of health, you know that the way you address the general population is very different from how you address readers who, as doctors, are completely familiar with the medical terms you use (more familiar than you yourself are). So I would agree with what Victoria Camps said when she pointed out that when we provide information, we have to take into account the intention, and that this in turn has to do with the audience. I think it is very important to always bear in mind, to keep to the fore, who the information is addressed to.

Regarding what has been said about the credibility of the media and the common sense of the population, this is certainly true. But I don't think the media is going through a greater crisis of credibility than at other times, because people's common sense will prevail. And, as we discussed earlier with Andreu Segura, when we talked about the Barcelona water supply, about whether it causes cancer or not, well it probably does because everything or almost everything causes cancer and people know that, because the simple fact of being alive entails being exposed to risk.

Marc de Semir. I will start with an anecdote, which relates closely to my day-to-day work, and to our work at the Hospital Clínic, and which continues with the hot topic this morning, which Cèlia Ribera has also referred to, the issue of water and cancer. The day after the appearance of this report in *La Vanguardia*, as often happens, we received lots of calls asking for a specialist opinion and comments on what was happening. For several months we had been considering introducing bottled water for patients, basically due to the bad taste of the tap water and so that patients didn't have to buy bottles (which the majority of them did). The decision to introduce bottled water was taken in the second or third week of August, which I think coincided more or less with this issue. I got a call from *La Vanguardia*, because a news agency had sent out an unconfirmed press release. I also wanted to send a message referring not so much to ethics as to professional criteria, to agree with Jaume Guillamet. Maybe it is more important to do your job well than to think about ethics. And this agency, without calling or saying anything, sent a press release to the whole Spanish media announcing that the Hospital Clínic in Barcelona had decided to provide bottled water as a result of the concern created in *La Vanguardia*. Well that's the anecdote. I won't tell you how many calls I had to take during the day, above all from *La Vanguardia*, who called me three times to confirm that this agency's press release was not true, and from the rest of the press. In fact, nothing was published, fortunately, mainly I think due to good management and above all because the rest of the media didn't respond much. Our concern was above all to defend our role as managers of communication. I am in charge of the communication office of one of the country's leading hospitals, and I believe we have a very important role as information managers and as the second filter of a public institution to pass the informa-

tion to the media. We very often just blame the media, basically the press – and in a moment I will discuss the other media – but I believe we should spread the blame a bit, and often the fault lies with a failure to transmit the information properly at the outset.

We should not lose sight of the fact, without exaggerating – I don't have precise figures – that the great majority of the news which appears in the media is the result of our work, or of information supplied by us. Only in very extreme cases of epidemics and the like does it arise from investigations by the journalists themselves. Returning to the question of criteria and the verification of information, the media seem to enjoy a degree of impunity; that is, they can say things and over time it fades away, and that's the last we hear of it. And something else which affects us very directly on a daily basis are letters to the editor, which are a double-edged sword. Apparently these don't have to be checked at all, and all sorts of rubbish appears on the basis that "it's the reader's opinion and the publication doesn't have any responsibility." But I think it's a very important weapon used by the media to put hospitals on the spot. We often encounter it, in very specific situations. And it's a bit like Chinese water torture, whatever answer you give afterwards, the damage has already been done, and I think that sometimes a letter to the editor carries much more weight, whoever has actually signed it, than half a page or a front cover in *La Vanguardia*, and even more so when we see how much credibility they are given.

Mariona Grau. From hospital to hospital, and now it seems to be the turn of the intermediaries. I believe it is important to discuss the role of intermediaries here, because this role can be performed very well or very badly, and it is very double-edged. The intermediary is not a neutral element, there are no neutral elements in this game, everyone has interests and the intermediary is still the spokesperson of an institution. We obviously work for institutions. I don't plan to justify myself by saying that I'm clean and neutral, because it's not true. Having said that, I don't think there's any place for the victim-mentality that people adopt. I don't think that urgency justifies any kind of stupidity. In the case of the 600 deaths as a result of water, the urgency argument isn't even applicable, because as we've seen the story had been cooked up over months. So what am I saying? That journalists are the baddies here? Not at all, I'm not

simplifying it that much. To be honest, perhaps we're all being a bit simplistic here, because this is a very complex issue, and it's clear that we are also defending the interests of an institution.

But that having been said, the mediator has another role, that of facilitating communication between different elements, and attempting to ensure the quality of this information. And not just that; I believe there is also a third function, which may be more difficult. Independently of the defence of your institution, as public hospitals, I believe our hospitals should become a source of experts without expecting anything in exchange. I'll explain what I mean. It's clear that everyone has to be rewarded, but it is also clear that as public hospitals we have to be able to respond and to find the experts required in the event of doubts when it comes to helping ensure that the information being produced is correct. We don't need to say "such and such a person from this place, an expert in whatever." As public hospitals, we need a source of people who are capable of transmitting this knowledge, and making it available to the person drawing up the information. In other words, we have to create synergy. Why do I say that? Because otherwise we are all operating in isolation. In the case of doctors, and Marc de Semir must know this as well as I do, we find ourselves in the same situation: that is, there are three types of people. Neutral people, who can become involved if you tell them it's important and interesting, and who work closely with the public, and whose functions include this one, who are the largest group. Then there is another group which is almost equally large, who are terrified of appearing in the media, and whenever a story like the 600 whatever comes out, all that does is reinforce these fears. Or, when you have managed to get them involved, as soon as something like this comes up they run away with their tails between their legs, and say "I don't want anything to do with being a source of experts, don't involve me in this kind of thing." And then there's a third group which is obviously the most dangerous, who we all know, who is the protagonist, that is, the person who's also pressing to sell whatever it is, not just their image and photo, although there are some who are that simple, who see the image and are happy, but usually there are lots more interests behind it. We all know that nobody is neutral, not even the transmitter.

When we talk about ethics I also believe that there is no such thing as a specific ethics for a specific profession or for a set of specific issues. Ethics, in this

case, consists of a “manual” of good practice, for everyone in their own role, whether as a good health professional, a good mediator, a good journalist, a good expert, on the understanding as I have already said – because I’m not naïve about this – that I know there are interests at play. But we can reach some kind of fair play agreement in one way or another, we all have a shared concern: the citizen. Of course, citizens are manipulated from one side and from the other. But if an agreed position is established from different angles, it could be the first step, a minimum basis from which to work. And, I should say that the water incident also had a big impact at Sant Pau Hospital, because people phoned us and said, “The Hospital Clínic is more careful than you, because it has changed to using bottled water. What are you planning to do?”

Gonzalo Casino. As many of the issues have already been raised, I would like to use a specific example of what journalists face to illustrate what has been said about the sensationalization of information, which has often already been distorted at its source, to see how far health information has doubled, as pointed out by Gemma Revuelta, because of readers’ interest in health issues or as a result of other interests. To illustrate a little what the function of journalists should be, and how they should best perform their job, I would like to refer to something which appeared right across the media. I think it was in 1999. It was an article published in *Nature* about short-sightedness in children under two years of age. It said that keeping the bedroom light on during the night for children under the age of two massively increased their risk of developing short-sightedness during the school years. This reached the media through the usual channels, email, confidential press release etc. Short-sightedness is not an issue of much significance in terms of morbimortality, referring to Josep Lluís Segú’s question, however it is reported. Despite this, because the study and the press release came from *Nature* and the issue appeared to be quite significant, I think almost all the media reported it. If in those circumstances you stop to check the information with an ophthalmologist or an epidemiologist, in this case not many would dare to contradict *Nature*. In any event, the majority of the media reported the information.

I went to the bother of looking at what *Nature* had published on the issue of short-sightedness and I believe that in its entire 100-year history it had only written about the subject on one occasion. So *Nature* was getting involved with

an area which went beyond basic science to address issues which were not part of the remit of the journal, to raise an issue which was reported in the *New York Times* and across the media. What happened was that the study was contradicted five or six months later in the same journal, on the basis that the sample selected had taken lots of factors into consideration but had not considered the genetic factor in myopia. It turned out that the majority of children in the sample had short-sighted parents. The subject wasn't raised again in the press until six months later, when *Nature* returned to it. In *Nature's* archives there were already half a dozen mentions, mainly letters, saying that this study had no credibility, that it was poorly designed, etc.

This makes me consider how the media information situation has changed, when a journal like *Nature* allows itself, in the first place, to publish this study, and, secondly, to select it through its communication agency (which is the most powerful one there is, as shown by its media impact) and to put it forward as one of the most significant issues. It strikes me as a perfect example of this spiral of sensationalism, even if it is not a major issue in terms of morbimortality. I think that cases such as this make up a large part of the body of information which has grown so dramatically over recent years, most of which should not have appeared in the media, while much of the other information is very technical, and should not have been covered either. But the fact is that these journals are dominant and provide information, often very one-sided, that journalists are not always able to evaluate by turning to other sources. All of this leads me to reflect on the function of journalists, and on the difficult role they have to play in filtering information. The example of *Nature* is a clear case of an article which should not have been published or which should only have been published with reservations. But nobody or very few specialists would be willing to offer a contrary opinion. So this filtering requirement, this interpretative requirement which is demanded of journalists, is not easy to perform. And when we talk about the ethics of communication, what we clearly mean is that everyone – as some people have already pointed out – should perform their work to the highest standards and with the best intentions.

Vladimir de Semir. Before handing over to Dr. Vilardell, I would like to make one comment. Many people must think, "If a journalist has good judgement, then he should be able to avoid being caught out." I've heard that opin-

ion from more than one person. But it should be said that the weight of the source makes it almost impossible not to be caught out, particularly when you know that the rest of the media will cover it (and then your boss will want some explanations). Maybe five months later the journalist who has decided not to publish or has proven to be more critical can say, “I was right,” but by then it will be too late. Only journalists with a lot of authority within their publications would be able to do that. One director of *La Vanguardia*, Paco Eloy, told me in his day something that made a real impression on me, although I recognize that it may not be good journalistic practice. “I don’t want any item relating to medical issues to be published without it having first been seen by Dr. Dauñ or Dr. Salgado,” he said, knowing that this went against something which is central to the journalistic profession, of being the first to publish news, and doing so as soon as possible. Ever since then I have been a firm believer that providing the information accurately is more important than being the first to publish.

Gonzalo Casino. What has been said works as a self-criticism not just of journalistic practice but of the whole system, because I think things start to go wrong at the source, which sensationalizes things and gives the press office permission to issue the press release, knowing that it will appear all over the media because of where it comes from. This is also a criticism of the sources who could verify or contextualize the news. In this example less so, but in other more delicate ones a lot of people might not be willing to do it, because they say, “How am I going to go against *Nature*? It’s not as if I have the article to give my opinion on it.” When you’re going to publish, the majority of the experts don’t yet have access to the article like the journalist does, who in any event can send it to them. But it is the system which is at fault and which has brought about this spiral of sensationalism, and I think it is largely this which has caused the doubling of the number of reports, as we’ve seen from the figures. So this leaves us with what Ferlosio calls “empty boxes which need to be filled”. I don’t think the number of reports can carry on rising like this. The medical information scenario has to mature, because otherwise there will be so much sensationalism that nobody will be able to provide anything more sensational. This sort of information will probably become more restrained and will start to get more sophisticated.

Vladimir de Semir. I don't know to what degree it is good professional practice for a scientific journal to aim to be both the most influential publication within the scientific community and also the most influential in the mass media. And that's what is happening. Gemma Revuelta pointed out in an article in the journal *Quark* that the current director of the journal *Nature*, Philip Campbell, on being appointed, stated that his aim was to make the journal the most influential both in the scientific world and in the media at large. I think this double policy is difficult to maintain without journalistic interests becoming tangled up in the peer review process.

Miquel Vilardell. I only want to comment on some of the remarks which have been made so far today. Firstly, we're talking about truth. I've heard some people say, "scientific truth does not exist." Clearly it doesn't exist, nobody is talking about scientific truth. What do we mean when we talk about scientific truth? That it has been published in a journal which has been subjected to serious critical review by experts. That is the truth, and maybe as days or months or years go by another scientific truth appears which contradicts the first one. There's no doubt about that, nobody can utter scientific truths, because they don't exist, they change and sometimes they are precipitate. Having said that, I don't agree with what's been said about *Nature*. Why? Why is *Nature* prestigious? It isn't for no reason at all. *Nature* is prestigious because that is the opinion of the scientific world, because it has published the best articles and because people know that *Nature* has one of the best and most demanding review systems. This error by *Nature* happens at all journals, but at *Nature* the percentage is very low. This article got through *Nature's* reviewers. What was the problem? The professionalism of the reviewer. Who did the review? Can the reviewer be held responsible or not? If I send an original article to two or three reviewers and the report of the reviewers, who are meant to understand statistics and be familiar with research design, misses out a factor as important as genetics in the case of short-sightedness, that is clearly punishable, and the reviewers who accepted the article for publication because it was of the right quality should be held to account, because once it's been published, *Nature* thinks it's fine, it's an article on a topic which sells very well, it's been through a critical review process so they send it out to the media. Who is holding people responsible for that? The article gets sent out to the media because *Nature*

is interested in getting itself known as a journal, with an issue which is very topical and affects a lot of people but which has, in any case, been through a critical review. The reviewer should be held to account. This means that we still don't do the criticism, the external review process, well. We need to perfect the external review and probably professionalize it too. A few days ago, I said to the editors, "You need to look for new sources of funding apart from the ones you're accustomed to, because in the near future you'll have to pay the reviewers." In our country there aren't any paid reviewers, and the reviewers for the *Lancet* and *New England* only receive a free subscription to the journal and the right to appear in an annual list of reviewers. So maybe this should be put on a more professional footing.

I will answer another question put to me by Andreu Segura, about what knowledge management is for. I'm not talking about this in the business sense. I think we need experts who analyze knowledge. Who should they be? Professionals, who by the age of 45 are probably finished in the world of research, because you have to be young to do innovative research. There are few people who after the age of 40 or 45 have carried out very important research, in the case of Spanish scientists. When have they done groundbreaking research? At an early age. There are studies which show this, just as there are studies which show that the best critical reviewers are people aged over 40, who know statistics, who know epidemiology, these are the ones who do the best critical reviews. Therefore, I believe that in knowledge management, these people who have been researchers, who are perhaps no longer as productive as they once were, would probably be ideally suited to reviewing the information which appears, they should select it a bit and give it to us in a digestible form. This is an opinion, and I would like to make these two points. I agree, however, that this is obviously not a closed issue.

Victoria Camps. I just wanted to say one thing about truth, and another about ethics and professionals. Earlier, I questioned the notion of truth, but I wasn't referring so much to scientific truth as to journalistic truth, which I think is another kind of truth. Because there is also a certain positivism in the press. I believe that scientists are much more sceptical regarding the truth. But one thing is the scientific article, signed by a scientist and in which he takes responsibility for what he says (and here there is indeed a way of showing

whether something is or isn't true) and another thing is the information which is provided not by an author but a reporter, someone who reports certain facts. What I question is this verification of facts, which can never be exhaustive. Earlier, Dr. Guillaumet said that the best way of transmitting information consists in knowing how to summarize in one's own words everything which is interesting or important. And this is an interpretation, and has nothing to do with the idea of truth or of fact-checking. I think this is what we have to consider when we talk of communication or information.

Next, as there have been a couple of interventions questioning the importance of ethics, I absolutely agree that ethics is nothing more than good professional practice and that there is no need for experts in ethics. I totally reject the idea that there are experts in ethics. There are no experts in ethics in the sense of people with more authority than others to say that a practice is right or wrong. What philosophers working in ethics do is know more than other people about what ethical systems there have been, what their basic principles have been, what criteria they have used, what concepts they have used, but none of this can be used to judge a particular practice. Particular practices should be judged by the people who carry out the practice, they are the ones who should have the ethical and professional criteria to judge them. We live in a world where there is a division of labour, and when a problem is typified as being an ethical problem the media call the professor of ethics to ask, "What do you think about this? Is it right or wrong?" The first thing you have to say is, "I haven't got a clue," because I'd need to study it before giving an opinion, not as a professor of ethics but as a citizen, if I think that seems right or wrong. But I think we don't make that distinction, instead we tend to do the opposite, to make people think there is a need for a figure, an expert. In the United States, that figure already exists, they already talk about ethicists and bioethicists, and that strikes me as terrible.

Ramon Bayés. In my opinion, any article or speech, any scientific journal however important it is, should be read or heard in the awareness that it could contain errors. In other words, we should always start from the basis that "the truth" does not exist in complete form in any human communication. I have just remembered some words which have been fundamental to me throughout my teaching and research career. Many years ago now, I read Bertrand Russell's

book, *Human Knowledge*, in which, after more than 600 pages spent analyzing the different scientific disciplines one by one, he reaches the following conclusion: “All human knowledge is uncertain, inexact and partial.” As a result, I believe, even if we are talking about *Science*, *Nature* or the *New England Journal of Medicine*, that whatever guarantees they offer we should read the articles in them in the awareness that their content may be true or only partially true.

From another perspective, I would like to make a proposal to the group of journalists here because, if it is successful, it would require an independent body to oversee it, and I believe that the people here fit that description. There is a classification of scientific journals according to their “impact ratings”. These are complex indicators, which are not yet accepted by everyone, and they show a gradation in the quality of journals, with a trend from lower to greater probability that the information they contain will be significant and accurate. My proposal is as follows. Why not create an ethical impact rating applicable to the media and which would be published on a regular basis? On the one hand, it could take into account similar data to that used to compose “the impact rating”, that is, the number of subscribers, print run or audience, number of subscribing libraries, number of countries it reaches, etc. It could also take into account the number of headlines which do not reflect the content of the article, repetition, the quality of the checked sources, etc. All the data should be quantifiable and used to produce a final number which would constitute an approximation, not perfect but approximate, to be included in an index of organs listed in accordance with an ethical quality rating. In order to reduce the pressures to which the group responsible for publishing these indicators would no doubt be exposed, the indicators could be based solely on positive elements. As happens with impact ratings, only those organs which had reached a certain level of ethical quality would appear in the list. At the same time, I believe that ethical principles are the same for all professions. In the case of journalism, I personally would propose an ethics of minimums, an ethics which, above all, is non-maleficent.

Antoni González. I just want to comment on one aspect of medical communication which is becoming increasingly important, and which I think we should be interested in or at least concerned about. That is all the information being generated by the information society, the internet, whatever you want to

call it. At times the doctor, the patient and the journalist may be the same person, that is, on a portal you may find the second opinion of a doctor, the patient participates in a forum of people suffering from an illness, and the journalist interviews a specialist. This generates a situation in which you receive information of every type, where you often have to compare studies with very different conclusions. Journalists who are dedicated to medical communication and who work on the internet, who once received four journals, now have a hundred articles in their list of favourites every day. And sometimes it's very difficult to know what merits an interview and what doesn't.

About a week ago international scientific journals got together and discussed all the review and verification processes and the like. The background to this meeting was an editorial which had appeared some days earlier, proposing a set of recommendations to guarantee the independence of publishing. I spoke to the editor of *JAMA*, and she told me, "That's right, we're very happy with this declaration and we've all reached an agreement, but look, let's be honest. Declarations are good for whatever you want to use them for, we can all sign up to them, but we all know when we're being honest and when we aren't." That is to say that ethics is often an internal issue which does not require any specific regulations. So there is a new information framework for medical communication, which has seen massively increased information flows, far more topics being addressed, and much more data. This framework, of symbiosis or whatever we want to call it, involves the patient with the information, with the journalist, and with the doctor. And from an ethical viewpoint this means that within this mass of information, problematic information is not just the concern of the sender and the receiver but of society as a whole, so editors have a much wider impact.

Antoni Plasencia. I would like to return to what Victoria Camps said regarding scientific truth versus journalistic truth, and frame it as a question as to whether we are asking too much of the mass media (radio, TV or newspapers), if we are asking them to perform a function with regard to medical communication which goes beyond what, by definition, they can achieve. We have already said that there is a sense in which scientific truth is comfortable with the idea of uncertainty, it works with this notion over very long time periods and through extensive debate involving agents such as scientific journals who

provide a degree of quality control. For newspapers, however, uncertainty is not really acceptable, things belong to one of two categories: either they exist or they don't (forgive me, I'm not a journalist and of course I'm simplifying things and introducing my own prejudices). And we can agree that uncertainty is not very interesting to transmit, because it is neither black nor white; and at the same time, as we have already noted, good news is not generally news, or at least not very important, and clearly, for reasons of space there is a pressure to simplify things.

While we were talking over lunch, somebody mentioned the degree to which some of the front pages of Barcelona newspapers are becoming victims of design. So my question is, to what degree are we asking too much of mediums which, by definition, by design, cannot transmit scientific information in an accurate and comprehensible manner? When we talk about this kind of information, maybe we are referring to the difficulty of ignoring some headlines, while by contrast – there are some people here with experience of this – the science supplements in the media, above all in the printed press, but also in other mediums, definitely have a role to play in disseminating information. What we are saying is that between the production of science and the daily media there should be some kind of instrument – one which in fact exists – an intermediary for disseminating information, which operates with procedures, with time sequences, with different periods, and which helps this communication process more and which has not appeared until now.

Salvador Alsius. When Jaume Guillamet and I were studying journalism, the students in another year were responsible for an event which is worth recounting. At the end of a writing class, the lecturer, who was also the senior editor of *El Correo Catalán*, said, “Well, for tomorrow, as always, bring me some news.” In the context of the class, this meant that they had to bring in a news report. But. While chatting over a beer after class, the students decided to take him at his word and the following occurred. That night at about half past ten someone rang *El Correo Catalán* saying that from his house he could see a UFO over the Tibidabo mountain just outside Barcelona, and he described what he was seeing in some detail. The person who took the call had barely had time to hang up before the phone rang again and someone else, calling from the Sagrada Familia Cathedral, described the same UFO, and so on until about

twenty people had called in, which was the number of students on the course in question. The next day the report of the UFO appeared on the front page of *El Correo Catalán*, because at that time of night the Fabra Observatory was already closed, they couldn't get hold of anyone, and it was obvious that so many people couldn't all be wrong. This shows that, when it comes to sources, the media has a glass ceiling. I always say that if in Barcelona there was a cell dedicated full-time to confusing the media, they would find plenty to keep themselves busy and would cause a massive impact, because whatever written regulations there may be about the need to check reports, the fact is that the dynamic of our daily work makes this difficult, because of the scarcity of resources available and so on.

Anyway, this thought leads in two directions. One is that journalists should always start from a position of humility, something which we rarely do. On the contrary, staff journalists tend to be self-sufficient, and the more serious the newspaper or the organ for which they work, the greater the arrogance, the more they say, "We do things really well, and nobody can teach us anything." Well, that humility is necessary. And at the same time, another obvious consequence is that of doubling our efforts to ensure that sources really are checked as far as possible. I agree with what has been said about how ethics is the same as good professional practice, professional quality. I would agree, as has been said many times, that ultimately journalistic ethics is no different from any other kind of ethics or from individual ethics. But I would like to introduce a distinction. Of course there are some general principles which should apply to almost all the different kinds of ethics which exist, but the basis of individual ethics will not always coincide with the basis of codes of professional practice. For example, many of you are doctors and you know perfectly well that your personal beliefs may come into conflict with your professional ethical responsibilities. I think this may apply to the majority of professions, above all to those whose professional ethics are based on a social right. And journalistic ethics – and I like to refer to journalistic ethics and in a moment I'll tell you why – should be based on society's right to information and not on the individual convictions of the actors, of the journalists in this case.

Apart from considerations of this type regarding its basis, I think there is another practical reason for talking about the professional ethics of journal-

ism. We have got the public accustomed to using this term and it would therefore be a pity if, as a result of statements like “no, it’s the same, ethics is quality, ethics is good practice,” we stopped referring to ethics and journalistic ethics, because the public already demands journalistic ethics. The taxi driver will say to you, “They went way too far in that programme! Don’t they have any ethics?” So it is a concept which society already uses and I think it’s worth keeping, above all for reasons of labeling or, if you will excuse the expression, ethical marketing. How should we implement this ethics or professional code of conduct? How should we meet the demand for it? I think the only way is by attrition, by which I mean we have to take advantage of every opportunity and every tool to ensure that one day the public, journalists, the media and sources all work together to the same end. What are the instruments? They are codes. Why codes? Are they essential, are they necessary? Probably not, but what is clear is that those of us who started out in this profession 30 years ago had a spontaneous education in ethics from our seniors working alongside us, there were very few of them and they were concentrated in a few editorial teams. You had your teachers who told you what it did and didn’t mean to be a journalist, how to do quality work. Today’s profession is much more dispersed, much more atomized, there are lots of self-contained positions, there’s remote working, there are a thousand different things, so it’s not so bad if a certain way of thinking is recorded as a code. Apart from the codes, there are ombudsmen, media observatories, information councils etc. (I imagine that as a result of Francesc González Ledesma’s contribution this morning, the existence of the Information Council has already been discussed.)

I would like to stress the importance of training. I refer once again to the old school of journalism. There was a subject called Professional Ethics. It disappeared from the curriculum because ethics, as Victoria Camps has explained many times, declined in general as a university subject as the curriculum became impregnated by certain ideological substrates which didn’t sit well with talking about morals and ethics. But this situation is now being reversed, and in this regard the people who draw up curriculum plans have become less cautious and have reintroduced subjects relating to professional ethics into some journalism faculties, and also by appealing to the notion of quality, and through specialization. Journalism studies tends towards the training of spe-

cialized journalists, although I think this should also remain within limits, because I'm one of those who believe that a journalist has to be something of a jack of all trades. But it's logical that in certain settings and given the delicacy of certain subjects a degree of specialization has been introduced. In the later stages of journalism degrees, where students have already completed some studies, some of the subjects are moving in that direction, and postgraduate courses too. So I think that's the way things are going.

Finally, I'd like to make a brief comment on the subject of the concept of truth. It is clear that there is no such thing as absolute truth, I'm sure everyone here would agree with that, and that it is therefore difficult to say, "We're defending the truth." It has to be said indirectly. But what is true is that truth is an ethical principle, a principle which cannot be replaced, as is often done, by that of credibility. I always say that credibility is how truth is marketed, but it can also be how lies are marketed. Just because something is more credible doesn't make it true. And, in any case, we're not talking about the truth but rather, as Marc Carrillo once said, of diligence in seeking the truth which, however partially, may lie hidden in things.

Vladimir de Semir. I don't want to finish without first raising another important issue: the perspective of journalistic practice itself. The role of the journalist is to inform, transmit knowledge, act as intermediary between different groups; there are lots of possible definitions. This evolution in journalistic practice has implications for the present day which I'm not sure we have considered with sufficient care. We are not only transmitters of knowledge, of information, creators of opinion etc. Now we also perform a job for which we have not been prepared: that of shaping the cultural lives of our audience. The omnipresence of the mass media in our society means that people increasingly learn what they need to know from what they see, hear or read in the media.

Andreu Segura. About a year ago the journal *JAMA* published a study advising against the accreditation of individuals to act as advisors regarding bioethical conflicts in the American healthcare system, specifically against a potential academic specialization. It is likely that the birth of clinical bioethics is related to the loss of social power of doctors, but clinical bioethics is not directly applicable to public health, because the two confront different prob-

lems. Clinical bioethics deals with individuals, and public health deals with communities.

An improvement in the quality of professional practice, of physicians, health professionals and researchers and, of course, of journalists should also improve the ethical aspects of their work. However, the comparison between professionalism and honesty can be misleading. From my experience of social institutions such as the Catholic church and the Communist Party, I have the impression that personal honesty, in the sense of its coherence with one's personal beliefs, with one's conscience, is not sufficient to ensure an ethically acceptable attitude. This is what can happen if "possession" of the truth implies imposing it on others or justifies a tendentious way of presenting the information. For this reason, it is advisable to respect certain minimum rules of play which, without restricting freedom of expression and of opinion, prevent interpretation from being confused with the facts. In this regard, an article which appeared in the weekend supplement of *The Guardian* this summer regarding the Spanish toxic rapeseed oil epidemic may be illustrative. The journalist presented the episode as a conspiracy between the Spanish government and some multinational industrial group, with the help of the majority of the investigators, to hide the real cause, which, rather than being the oil, was treatment with pesticides. Any reader lacking a thorough knowledge of the situation would have been completely convinced by the interpretation offered by a journalist who had probably become caught up in the same web of illusions which he was supposedly denouncing by constructing a coherent, convincing explanation, as often happens when conspiracy theories are put forward, regardless of whether they are true. And this is why we need to respect the rules of the game and to be transparent.

With regard to the example of *Nature* cited by Gonzalo Casino, it must be said that articles containing errors will inevitably appear, whether in *Nature* or elsewhere. It seems likely that the editors decided to publish with a mind to the social consequences. And not surprisingly, given that the article, if correct, would have had major practical implications for health. As Jordi Camí said, this is one of the dangers of a "journalistic" vocation on the part of scientific journals. But neither should we mythologize science or any of its products, because medical decisions should be taken on the basis of information drawn

from more than a single piece of research. The problem is that the publication of these results may encourage their premature incorporation into health practice. In these cases, the opinions of independent “experts” may help to improve readers’ understanding of newspapers. But it is difficult to find someone able to criticize an article which he or she has scarcely been able to read. In any event, and with regard to public health, this difficulty increases because the majority of professionals are not independent of the public authorities. In a sense, their situation is somewhere between that of hostages and accomplices, which tends to encourage them not to take part in public debates, just in case. And this is very serious, because public health is one of the areas which most needs independent professionals with public credibility.

Before I finish, I would like to endorse Ramón Bayés’ initiative to defend our interests as consumers of scientific and medical information. In a way which is similar to that of the reader’s advocate on newspapers, there may be a convergence of interests between the media and consumers which provides a basis for criticizing the way news is handled and the dissemination of potentially undesirable consequences for people’s health and well-being.

Xavier Carné. I would like to clear up a moment of confusion which occurred over lunch. I couldn’t go home at ease without commenting on what Miquel Vilardell said this morning regarding the fact that today’s medicine is evidence-based. Victoria Camps knows that we have been criticizing evidence-based medicine for a while now. And I would like to give an example, which is just one of many, which illustrates the problem of the modern medical paradigm, that of evidence-based medicine. Miquel, I imagine you will agree with all the steps of the argument. Evidence-based medicine states, as its first paradigm, that the best scientific method is a properly conducted clinical trial, with random allocation, comparative groups, a large *n* number, and so on. However, there are a lot of multinationals, two in particular, which are really selling the idea of evidence-based medicine to crush much smaller companies, saying, “We produce evidence, you don’t.” Two weeks ago – for me this is a great example – the *New England Journal of Medicine* published three very well-conducted clinical trials, by North Americans, multi-centre, so they can’t be criticized on methodological grounds, on angiotensin II receptor blockers, for the “sartans”, a group of drugs which block angiotensin in type 2 diabetes, which is

very common, and hypertension. The three trials are immaculate, it's difficult to criticize them, but the three trials are accompanied by an editorial which says that, while there's nothing wrong with them, "There is a group of medicines we've forgotten about, which inhibit the enzyme which precedes the product pathway, the ACEIs, the angiotensin converter enzyme inhibitors. These, with all the evidence we have, and there's a lot, would probably do the same, and they cost from 10 to 100 times less." That's what the editorial says, and why haven't trials been conducted, those large, well-designed trials to demonstrate the great benefits of these other products to Dr. Segura's public health? Simply because all these products, the ACEIs, are not protected by patents, cost a couple of dollars, and the sartans have 10 years of patent-protection ahead of them and don't cost a couple of dollars, they cost a lot more. Conclusion: the editorial writer's impression is to say, "Gentlemen, as I scientist I believe that, although there is a small advantage over ACEIs because they cause less coughing (but that's not very significant in the population) apart from that, we can get by with ACEIs." But nobody anywhere has performed these trials with ACEIs; they've done it with sartans. Why? And I asked the companies which have done the trials, how much did they cost? 21 million euros. Who invests 21 million euros? Someone who expects to make a profit. It's easy for sartans to make a profit, if they are shown to work, and they have been, and the ACEIs haven't. So we have to be careful with evidence-based medicine, it's the paradigm for modern medicine, I agree, but he who pays the piper calls the tune. And you all know that 90% (somebody said 70%) as a minimum of multi-centre clinical trials published in the world are sponsored by the pharmaceutical industry, if not more, because the ones which aren't openly sponsored are often covertly sponsored, because lots of those which are promoted by Dr. So-and-so have a multinational company behind them. So, evidence-based medicine, yes, but we have to be careful, because it's also a trap, and who pays for medicine in our country? Europe. Who pays for treatment of type 2 diabetes with hypertension? The state has to spend millions if it wants to follow the rules of evidence-based medicine by paying for sartans, which cost a lot of money. Probably the ACEIs would be sufficient, and we'd save vast amounts of public resources and money. Miquel, you know I've spent 20 years working with clinical trials, and I'm a great defender of the method, among others. But let's keep things in perspective. He who pays the piper calls the

tune. We need to be careful with evidence-based medicine because the promotion of clinical trials is almost exclusively in the hands of the pharmaceutical industry, and they investigate what they want to, and what they don't want to investigate doesn't get investigated. And there is no public investigation of cheap medicines which don't bring profits but offer great public health benefits. I've spent 10 years trying to do so, with failure after failure, and I'm not the only one, there are a lot of people involved.

Miquel Vilardell. I was afraid you didn't believe in evidence-based medicine, but I've seen that isn't the case. What you didn't describe are the biases in evidence-based medicine, in clinical trials, and I also mentioned that this morning. And I gave the example of the 25 billion dollars the pharmaceutical industry allocated to biomedical research with clinical trials in the United States in 2000. So, I agree. Now, when I was talking about evidence-based clinical practice I did it because doctors, in response to being overwhelmed with information and because politicians are concerned with costs, and costs arise from variations in clinical practice, logically need protocols and these are based on scientific data, on well-informed sources, on meta-analyses of studies, etc. It's not acceptable for me to treat a neoplasm of the prostate and for this to cost 60 euros, and for someone else, the same process, to cost 600 euros, just because I believe that neoplasm of the prostate should be accompanied by an MRI scan, and I'm not talking about drugs. So we do need evidence-based medicine.

The great pity is that in medicine and science we don't have much evidence; gradually more will appear, but we have a lot of gaps. I agree that the interests of the pharmaceutical industry are very powerful, but I also agree that scientific societies and the authorities should invest resources in these clinical trials that nobody does. And there are very few clinical trials with old people or clinical trials with low-cost products. Where does the idea for the research and the clinical trial come from? From the company or from the principle investigator? I think it should come from the principle investigator, when he thinks of questions which he would like an answer to. And the investigator is the one who formulates a question which someone has asked him, a doctor or whoever, and which he wants to answer. And, therefore, I think that the state – and, as you well know I've been with the Spanish Agency for Medicinal Products for years –

something which has always been lacking in our country, and even more so in others, is the lack of initiatives and money to conduct clinical trials without the intervention of the pharmaceutical industry. I think that's the real challenge.

Óscar Vilarroya. I'm not going to comment on the last intervention, even though I would like to, because I want to respond to the last part of Andreu Segura's contribution regarding specific proposals, so that we can end the session by giving some kind of indication as to how things should go. First of all, I agree with what Victoria Camps said this morning, and I disagree with Salvador Alsius's comments. I believe that ethics should be integrated with good professional practice. I don't see ethics as something extra, as I said this morning. Otherwise, we could say that a journalist could exercise good professional practice while being unethical, or a journalist could be ethical but be guilty of poor professional practice. What we are referring to here as ethical considerations should be integrated into the structures of professional practice, and yes in many instances that should involve drawing up codes of professional ethics like that of the Medical Association. However, these ethical considerations, in my opinion, are not distinct from what constitutes good professional practice.

Therefore, the specific proposals should focus not on a prescriptive activity, which might be the natural tendency, but rather on promoting good professional practice: to provide better teaching for journalists, to give them more and better tools to do their job better. For example, a few years ago the Medical Association made a proposal (I'm not sure if it has been followed up) of offering itself as a kind of auditor of medical websites. The aim was to ensure that the information provided was appropriate according to evidence-based medicine or a good empirical case history. I think this was an excellent proposal. Another specific proposal is to create what they have in the United States, with internet-based networks of experts. There could be a crisis unit at the Medical Association or at other institutions, where the journalist could send messages at any time of the day or night saying, "I've got this information, could you please comment on it ...". Of course, this wouldn't resolve many of the ethical problems because, as Andreu Segura has said, they might call an expert to have a black and white answer, and not accept that the news item should respect the shades of grey in the scientific information.

Another concrete proposal is to create working groups to respond to the questions which Gemma Revuelta put in one of her articles, and which she calls “the interrogatives”, which are the questions which need to be answered during the day-to-day practice of scientific journalism. Some of these can be answered, others perhaps not. However, these are the specific problems we should discuss at this meeting. “Should information be provided regarding the results of a treatment which has not yet been tested on humans? Should these results be the grounds for large headlines or even front page coverage? Should experts’ ‘off the record’ opinions and forecasts be reported?” These are specific issues which should be discussed in settings such as this, and indicative answers given, or general guidelines at the least.

What is at stake is good scientific journalism which, as Dorothy Nelkin very clearly defined it, is one which increases the ability of the public to evaluate scientific issues, and of the individual to make personal choices. Against this, bad journalism disorients and disempowers, leaving individuals without the capacity to react. Vladimir de Semir also offers a definition which I find interesting: the specialist journalist must fill the vacuum which exists between the production of knowledge and the opinion of the audience which receives it.

Miquel Treserras. I would like to highlight one ethical issue. The problem is one of language, which is a source of both possibilities and obstacles. The question, as I have said, is of an ethical nature. Scientists normally assume that objectivity is possible, that language can express reality precisely. Their hypothesis is that language is unequivocal, clear and distinct, and they adopt it as a system for representing ideas and communicating them. The members of a research team know what they are talking about at all times. Each term and phrase has a unique meaning, and they work in accordance with the principle of objectivity. However, neither journalists or ordinary people, in the street, at home or at work, use language in such a rigorous manner. What’s more, the specialist terms so common in scientific language – objective, unequivocal, clear and distinct – lack meaning or have very little meaning. Ordinary people use language which is ambivalent, multifaceted and vague. When the journalist writes an article, his text is susceptible to many interpretations. The same is true of political speeches or in conversation. The scientist seeks to avoid confusion, while daily language plays with a degree of ambiguity. And not only is

this not a problem, but it is seen as enriching the language. This gives rise to a problem: researchers and communicators use two very different languages. Does dissemination trivialize? Is research a closed realm of knowledge? Doctors, when talking to their patients, don't employ the scientific language found in scientific articles and texts but instead use vague, day-to-day, ambivalent, multifaceted language. This is the problem, a problem of "translation", of a change of key, of register, which also evokes an ethical question.

What role does ethics have in this problem? I believe that journalists cannot be exact or objective, and they have to know to what extent their point of view is an interpretation. It may be very close to the truth, but it may not achieve it completely. To strive for complete veracity is to aim for something which is beyond our reach. We should be satisfied with being honest. The person who is speaking should be, as the ancient Greeks and Romans used to say, a virtuous man, a person of good conduct. Honesty is inseparable from intelligence and goodness. If we can't be truthful then we must be wise and honest. That is the ethics of the journalist and of the communicator in general. I also think it is the ethics of the doctor when talking to his patient, or of someone who talks or writes in the press, in the media, on TV or radio: both should at least try to be honest. Being honest in one's use of language involves being very careful of the pitfalls involved when using ordinary language. Warm, multifaceted language, full of implicit content, emotion and a multitude of expressive signs, can show or suggest ideas, or it can be confusing, obscure or become meaningless noise.

When I address the public I believe that my first obligation is to try not to fall into any of the pitfalls of language, such as half-truths, confusion, clichés, brilliant but twisted reasoning, empty words. And I think that doctors should also try to be as honest as possible with their patients. Rather than the ethics of journalism, I believe in the ethics of language. For me, ethics has two chief spheres: economics and language.

María Casado. I would like to highlight the apparent agreement between different speakers and add to this. I refer to what Salvador Alsius has said regarding the notion that the essential element of journalistic ethics is its correspondence with the right to receive information, which is a fundamental

right. The right to give accurate, relevant information is also a fundamental one. One of the things which makes these interdisciplinary exchanges important is that they help us to put issues in a wider context, such as that of constitutional law. The Constitutional Court, when it decides whether, in providing information, a person's reputation or privacy have been violated, takes into account not just the veracity of the information but also its relevance with regard to its impact on the lives of the people involved and whether this information contributes something to society as a whole. I think that in this context we could identify guidelines which would enable us to clarify situations and concepts.

In addition to this obligation of journalistic ethics to take into account the relevance, impact and context of the news being transmitted, I also believe it is necessary to be more explicit when it comes to identifying any underlying conflicts of interest; it is important to "identify oneself". I believe this contributes to transparency, and in the end transparency means making a contribution to real, social democracy. If we settle for the formal rules of democracy, we might say that we're already there, but if we really want our society to function democratically, then transparency is a very important requirement.

And, finally, there is one more question I would like to put on the table for discussion, something which was mentioned this morning but was pushed aside by all the other issues which came up. I refer to the importance of individual responsibility and the guarantee which a byline provides with regard to the reliability of news, particularly in the context of the information circulating over the internet. I fully agree with what Jaume Guillamet said in this regard, and I believe that we must stress the need to make it clear that information appearing on the web has not always been checked. In addition, the horizontal nature of the medium means that the reader, if he or she is not familiar with the field, may not have the tools to rank or evaluate the information they are reading. It has been proposed, and I would agree with this, that websites should be accredited by institutions, professional associations or scientific societies, with the aim of having some indicator of the reliability of the content. I think this is a new issue, and it would be a pity to miss this opportunity to discuss it.

Vladimir de Semir. I don't know if this is an overambitious proposal, but as several suggestions have been made, why don't we go further? Why not attempt to organize them? I'm going to ask Francesc to speak first. I'm sure that many of you didn't know of the existence of the Information Council, an organization with a degree of influence in the world of information.

Francesc González Ledesma. I'm sure we can reach some conclusions, because the discussion has been very wide-ranging, very enlightening, and I guess that recapping different points of view could provide a useful summary for everyone. As someone who wishes to be a servant of the truth, I should humbly recognize that the truth does not exist, the truth is always grey, it is never black and white, and when the truth appears to be straightforward it is usually being promoted by interests, and this means that it is suspect and has to be analyzed. I would accept that on the basis of everything which has been said here. I think that in this regard we all agree that at a minimum truth needs to be analyzed, above all scientific truth, which is never an instant truth but rather appears over long years of research, so affirming a scientific truth on the basis of a fact which has not been properly checked is reckless. Now – and here I speak as a journalist – I am aware that while truth does not exist in a pure form, it is reflected as it appears in the media. That is, people receive their truth from the media. This gives journalists a huge responsibility, and this responsibility extends over time, because the historians of tomorrow will read the newspapers which are published and will listen to the TV and radio programmes which are recorded. And this is why we need an ethics of journalism which is reflected in a set of guidelines, which is not just a personal opinion.

And permit me to disagree with what some people here have said; I believe that ethics should not be confused with professionalism. Professionalism is good performance subject to certain professional standards but not necessarily to ethical standards, which for me stand above professionalism. I repeat that just now there is a professional code which states as a basic standard that all information must be verified. That is, if I talk of scientific truth I need to strive as hard as possible to ensure that it is comprehensible and more or less true. But if the informer, for whatever reason, after all these precautions, is wrong, if the Information Council, which has many eminent scientists in its ranks,

reaches the conclusion that this information is wrong, the newspapers should be obliged to issue a correction in favour of the reader and the truth.

Salvador Alsius. Earlier I used the expression “Chinese water torture” to refer to the set of instruments which exist, and there are lots of them, and after spending a lot of time taking part in discussions and debates of the same issues, I’ve realized that our knowledge of these is very compartmentalized. So, you go to one place and they know that there are readers’ advocates but they have never heard of the Information Council, and in another place they discover the need for a journalistic code, while others say, “that already exists, the code of journalistic ethics.” Some base it on the conviction that you need to talk about ethics, others don’t; and in the end you realize it’s a question of words. All in all, I believe that, rather than defining new instruments, what we have to do is articulate and give content to the existing ones. So, I think Ramon Bayés’ proposal is an interesting one – I don’t know how far it would be implemented as he has set it out – it strikes me as quite similar to what you do at the Scientific Communication Observatory, where you sometimes issue reports of how the press treats scientific news; and the Information Council sometimes issues rulings on specific cases but sometimes also compiles more general studies. I don’t have a fixed opinion on whether we should talk about professional codes of conduct or ethics. There comes a moment when one set of words means much the same as the other, referring to Óscar’s comment. But if we say, “let’s take Gemma Revuelta’s questions and answer them,” then in the end what we’re doing is writing a code, whether you call it a professional code of conduct or ethical or whatever, for the sphere of medical and scientific communication. In other words, it would be a kind of baby of the more general code of professional ethics, just as there is another baby, which is the code governing the treatment of issues of racism and xenophobia, which already exists. So, we generate these instruments, using one set of words or another, which more or less pull in the same direction, and you have to make a huge effort to articulate it, and disseminate it, and make sure this task doesn’t overwhelm you. Next Saturday I’m going to be talking about journalism in a medical context, at a conference in Palma on palliative cures, and I’ll have to come up with a way of stitching the two things together. I won’t miss the opportunity to tell people about the Information Council and to reproduce a few of the things, some of the things

I already knew and others which I've heard today and which are also relevant. So, the articulation of convictions and efforts is central.

Cèlia Ribera. Well, sidestepping the issue of ethics, a professional ethical code, or good professional practice, which I think we all agree on because we want to do things as well as possible, I would argue that information in the general press on issues which affect people's health should be provided in a way which is formative, in the sense that it should be provided in a way which does not cause harm, which respects the principle of non-maleficence.

Jaume Guillemet. This is not so much a conclusion as an observation. I have observed that throughout the day, whenever we have talked about journalists and the media, what people are really thinking about is newspapers, and only newspapers. As a newspaper man, or at least a former one, and never a radio or TV man, I cannot be accused of bias, but I believe that when we talk about journalism we should not only refer to newspapers. Obviously Gemma Revuelta's talk was based on newspapers, but beyond that I have noticed that people always talk about newspapers. And I think that this means we aren't paying attention to the audiovisual media, which have more social impact, and which have the biggest effect on people. And at the same time we could fall into the trap – and this is a personal opinion – in which the newspapers also find themselves. I believe that the newspapers continue to operate as if they were the dominant media. And I think the papers should have changed a long time ago but they haven't. The only thing they are concerned with is providing the same news as the TV, what Umberto Eco calls “the bear hug”, because the papers should keep away from the bear, and the bear is radio and TV. And in this sense, when there is a chief editor who says to his specialist editor, “Publish this because X is also going to publish it,” he is making a big mistake because I would like to believe that newspaper readers, who are a specific segment of the public, want quality from the newspapers, not quantity. Obviously the papers can't stop providing broad coverage of the big news stories each day, but they should be capable of not providing news which they're unsure about, and not talking about it until they are sure if they have to provide it or not. In any case, let's try not to think only about newspapers when we talk about journalism.

Vladimir de Semir. What happens is that I guess that the presentation was an example of, well, if this is going on in the newspapers, imagine what happens in media where *fast thinking* is more ...

Jaume Guillamet. Oh no, oh no, oh no...

Vladimir de Semir. It depends.

Jaume Guillamet. Now I could really stick my neck out in defence of radio or TV and I wouldn't be suspected of bias.

Vladimir de Semir. It depends which programmes.

Jaume Guillamet. Oh no. There are very interesting scientific programmes on the radio, and on TV too. And radio and TV programmes are less likely to provide pressured treatment of delicate information, in the way that can happen in the newspapers.

Ramon Bayés. It strikes me that on radio and TV it would be relatively easy to establish a system for checking tricky information for broadcasting and where there is no avoiding the need for speed, by using the internet to consult a small panel of three experts – three independent judges – on issues of public health. It would probably even be possible to have panels specialized in issues which affect a lot of people, such as cancer, AIDS or old people. In this regard, there could be an advance review of reports using a small number of pre-prepared systematic questions to be addressed to the whole panel, such as “Would you change something in the report to be broadcast? If so, what would you change and why? If not, why not?”

Óscar Vilarroya. A short comment to support what has been said regarding the notion that newspapers are a minority medium. In the article in *The Lancet* which I mentioned this morning, on Di Bella's therapy, 62% of the patients had found out about the therapy through TV, and only 25% through the newspapers.

Returning to the question of the proposals, I should say that I am not a hardliner when it comes to the issue of professional codes of ethics, either. I am very happy that there are professional codes of ethics, but I don't know how

many of the doctors present here today would be capable of reciting the ethical code of the Medical Association, or even any of its articles. In any event, I would propose that someone – and I would encourage the Foundation in this regard – should attempt to answer the questions I commented on earlier and which Gemma Revuelta formulated in her article. Perhaps this could lead to the creation of mini professional codes, with the questions and answers to be changed each year. I believe we need expert people to get together and propose when the result of a clinical trial should be published, and what its value is. I repeat that the Foundation could be a good platform for this type of initiative.

Dulce de Fuenmayor. It is true that we have focused greatly on the newspaper world, on the press, but there are many other media challenges which affect people much more closely. I would talk in particular of the radio. This is a medium which is very close to people, because you can have it on when you are doing something else. You have to give TV your full attention, but radio keeps you company. I'm one of those people who put the radio on when they wake up. I try to find out about things at the start of the day. There's something I have often observed on the radio, which is the introduction of messages which are really advertising but which are presented as health news. And this occurs very frequently on the radio, specifically, which is the typical medium for concealed advertising which creates real confusion among people who are not health experts as to whether they are being informed of a scientific innovation or a miracle cure. That also happens in the papers. I clipped something from a newspaper which said, "Noni, the exotic cancer remedy," and there was quite a long article, from a magazine called *Prevenir*, and at the end of the article it said, "and this exotic plant can be taken as juice or capsules," and then came the advertising. But it is true that this happens far more frequently on the radio. And above all because it involves important people whose voice lends credibility to a kind of game in which listeners who are ignorant of health issues don't distinguish between whether they are selling a product or providing news. And this happens too frequently in radio, specifically.

Victoria Camps. To continue with what Salvador Alsus was saying, this issue was discussed a lot during the first stage of the Information Council, not the advertising mixed with health issues but with other issues, advertising which is not presented as such. I just want to say that there are bodies which

could address these issues, they could even make decisions, they could create opinion about what has to be done in certain situations. But those bodies are not used sufficiently because the Council only acts at the urgings of others, that is, at the urgings of people who ask questions, who make complaints, and if that doesn't happen, the Council doesn't act. It is therefore a pity that we have these bodies which could address these issues but which are underused.

Dulce de Fuenmayor. Perhaps we should start to ask whether these bodies should take more steps, and not just when requested to do so, if they should directly criticize the ethical behaviour of the media, but then it would still need to be published, and that's another issue, because not everything gets published.

Salvador Alsius. I'd like to make a small contribution to what has just been said. The Information Council – and Francesc will agree with me – was created to monitor the degree of compliance with the code of professional ethics, without wishing to interfere in the terrain of positive rights, but in any event with scarce resources. The Council took as its model the British and Swedish models. When the chairman of the British Press Complaints Commission visited, he told us that they issued an average of 600 rulings per year. So they have a major industry producing decisions. In the Swedish case, the figure was around 60 per year. We were very happy that during the first two years we had an average of 25, because it was a sustainable amount given the resources available. The Council is financed by the media which has signed the protocol accepting the moral authority of the Council, but problems are also beginning to appear, in the sense that there is a degree of demoralization among the members of the Council because they can say whatever they want when it's a local paper, but things are more difficult when it involves big papers like *La Vanguardia* or *El País* – some things have to be said.

Gemma Revuelta. As an example, in this body, to which a range of companies belong – I believe it is the Association for the Self-Regulation of Advertising – in principle there is a commitment to respecting the decisions and rulings it issues. However, there was a specific case which also involved health issues. It was a ruling which referred to a tobacco advert, by Tabacalera Española, in this case. There was a series of adverts which the association con-

sidered violated ethical principles, and recommended that they be terminated. The next step was that Tabacalera withdraw from the association. What I want to illustrate with this is that the process of ethical reflection, of professional ethical guidelines, is no use if it can't be enforced on criminals or "baddies". By contrast, it is not necessary for those who are very clear about what constitutes good professional practice and is interested in quality. But 99% of the population are in the middle between the goodies and the baddies. Many of us are grateful – I speak personally – when there is a framework which shows us what others think, majority attitudes, and in this case it is necessary and useful.

Antoni González. Along the same lines as what Salvador Alsius and Óscar Vilarroya have already said, I think that in addition to a code of ethical principles and theoretical questions, it is possible, or at least it strikes me as viable, that in media information a protocol or good practice guide could be standardized, a bit like the protocols used in medicine. So, for example, it should set out the correct way of providing medical information, that is, with as much objectivity as possible, given that this will always be for guidance only and in accordance with consumers' tastes, given that everyone has their own opportunities for applying and implementing it, perhaps some companies can't but others can ... But I'm in favour of codifying this professional practice.

Josep Lluís Segú. Three very brief comments. I love the idea of an ethical impact rating. Right now I can't imagine how to do it, but the idea strikes me as very creative and I'm looking forward to thinking about it. The other thing, and I'm referring here to scientific journals, is that I think something relatively simple we could do to clarify things greatly regards the issue of transparency; if we could find a way of getting people to explain what interests they are really defending or what interests could influence what they write. This measure would be easy to apply from a technical perspective (some international journals have already done it) and it would provide a lot more transparency, a lot more clarity when it comes to knowing which side everyone is on.

I'd like to end with one more comment, which already came up regarding the issue of experts on the TV which someone was talking about. We tried to learn from the experience of BSE. We suspected that even doctors only found

out about BSE from reading the paper or watching TV, because there was very little scientific literature. We tried to write the odd article in *Medicina Clínica* talking about BSE so that doctors would at least have a professional information source. The same experts who talked about BSE on TV didn't want to put in writing what they said on TV, to appear in *Medicina Clínica*. I give this by way of an example, which people may find illustrative.

Miquel Tresserras. Regarding the conclusions, I think one of these could relate to a media offensive. On TV and radio and in the papers, there is a considerable margin of freedom, very considerable, despite all the pressures which are so rightly criticized. Readers, viewers and citizens in general are interested in health. Health is much more interesting than politics. Maybe institutions, such as the Medical Association or foundations such as this one, should make themselves more readily available to the media to provide information about illnesses, new treatments, prevention etc: intervening in the media to provide information and to explain the consequences which derive from this information. These interventions need to respect the rules of each medium, avoiding tedious or banal contributions, or mere publicity. In summary, among the conclusions of this meeting I would also propose a media offensive.

Gonzalo Casino. I would like to underline or emphasize three or four areas which I think are weak points of journalistic practice, and very briefly say that we have to be particularly careful to ensure that the news agenda, the content which will be published, is not conditioned by others. This strikes me as basic. Right now, what with world days and other ploys, it seems that every day you already know what you can and can't talk about. Someone has to defend the autonomy of their own news agenda. This means saying no to a lot of information, and involves learning how to say no to a lot of reports which on the one hand appear to have a degree of credibility but which at the same time are incomplete or biased, and this would help to break down the uniformity of the news media, which I think is greater than ever. Another weak point which we must consider is the need to follow up information. I think this has already been mentioned. Once the news is published it should be followed up, because there may be errors which have to be corrected or it may just need to be followed up. And finally I would like to say that it is important to emphasize jour-

nalistic practice, above all the need for contextualization, to provide clues, to give a setting, more than just the news.

María Casado. I would like to stress how important it is to respect the key requirements of journalistic ethics, which also apply to biomedical communication: selection, rigour, following up reports, and placing special emphasis on the need to be careful not to generate false expectations. To do this we need to abide by a careful formulation of the precautionary principle: in case of doubt, always be cautious and don't sensationalize the information, as Vladimir de Semir recommends.

Regarding what has been said about the need for experts to give opinions which help clarify news items, all I can say is that our Bioethics and Law Observatory aims to respond to the media when asked to do so. This is part of a commitment by the University of Barcelona, which sees the provision of this service as part of its contribution to promoting relationships between university and society. However, I cannot help warning that on many occasions the effort which this availability represents is poorly rewarded. Often, after giving an explanation which we hope is both comprehensible and informative, we are asked to give a "yes or no" answer (on surrogate mothers, to give an example) even though taking such a simple stance is, in most cases, incompatible with the sort of considered analytical approach appropriate to intellectual work. We need to draw distinctions; the answer is probably neither "yes" or "no", but "it depends"; it is "yes, but ..." or "no, however ...".

Finally, it is important to emphasize the need for transparency about where the information comes from; not just the journalists, but the scientists, the sponsors, the laboratories and so on. I believe that this makes the information more credible and trustworthy, because it gives people the clues they need to judge the scope of what they are reading. Another issue is that it is easy almost without thinking to give people the impression that what is being discovered is already within everyone's reach. This has a major political impact: the fact that something has been discovered does not mean it is available, and for it to become available requires the efforts of many individuals and of the health system as a whole. In other words, a political decision is required. I think this is an important point.

Vladimir de Semir. A lot of interesting things have been said today, and I will do my best to ensure that all the proposals and ideas which have been put forward are reflected in the final document. I hope we can all have more day-to-day involvement with these issues, and I would also encourage everyone to make use of the institutions which we now have and whose capacity for action is gradually growing. There are also other tasks, such as raising awareness among the heads of the main media organizations to improve the range of high quality scientific and medical programmes, increasing the resources allocated to medical information, particularly in terms of quality (but also in terms of quantity, when we think of the small number of people who must cover this information in the media). In sum, I hope that this report will reach those who have the capacity to make decisions and to take action.

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