

# Ethical questions arising from the transmission of scientific information concerning research in biology and medicine. Report.

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## Opinion

In the field of research in biology and medicine, more, perhaps, than in any other, the number of items of scientific information produced and transmitted is growing impressively, and large sections of the public are showing increasing interest in this information. This means that its reliability and honesty are becoming real social issues in four domains :

cultural and civic : the issue here is the correct understanding by each person of scientific procedures, biological realities and perhaps most important, of man himself;

political and economic : as this sector of scientific activity commands considerable collective resources, the nature of and justifications for a programme of research must be made clearly comprehensible to public policy makers and more generally to the citizens;

medical treatment and health : information in this field is constantly needed by medical prescribers, and depending on its quality, it is liable to have marked effects, which may be favourable or harmful, on the behaviour of individual or collective users of new treatments;

ethical, for all the above reasons, and for yet another reason of no little importance : biological and medical research involves social and human aspects or effects which pose moral problems. Intelligible, accurate and honest information on the scientific data underlying these aspects and effects is therefore a prerequisite for the personal reflection and public debate which these problems necessitate.

## **Traditional difficulties and the emerging crisis in the transmission of biological and medical information**

By the "transmission of scientific information" we mean here the conveying from the researchers to the public of all information concerning present or planned advances in scientific research and the interests involved. The present opinion will therefore not deal with questions concerning the diffusion of established scientific knowledge through channels such as education, publishing and the various forms of popularization, as these questions are distinct from the subject dealt with here, although they may be related to it.

Although the transmission of information is never simple, the transmission of scientific information is usually beset with difficulties of a special kind. As by nature a new result of research cannot honestly be made to correspond to an item of factual information, its conversion into a piece of journalistic news, with the need for speed, simplicity and even drama which this implies, always involves a certain risk of falsification. In addition, as the result in question can as a rule only be fully understood and assessed by specialists in the field concerned - which is why the normal place for its initial publication is the specialized scientific journal with a committee of readers - it has to be stripped of its esoteric character to become intelligible to broad sections of the public, and this creates tricky problems of presentation and commentary.

However, a growing number of recent occurrences, including rash announcements, the withholding of information, cases of self-seeking complicity, attempts to manipulate policy makers, and the blatant spreading of wrong ideas, give reason to think that new deviations are now being added to the traditional difficulties of transmitting scientific information, deviations which are especially disquieting in the fields of biology and medicine.

There is every reason to connect this unprecedented situation with the considerable changes which have come about and are continuing in the activities of both science and the media.

The scientists' longstanding attitude of suspicion towards the press, radio and television, which still predominated at the beginning of the seventies, has fortunately been tempered by the feeling of having a special social responsibility and the duty to inform the public of the results of their research and of the interests at stake. But concomitantly with the favourable effects of this feeling of responsibility, the new relationships between researchers and journalists have given rise to new forms of malpractice, which have emerged with the growth of institutional pressure to publish, and the intensification of various forms of competition for means to finance research, competition in which the support of the media constitutes a major asset. This is the origin of many cases of scientific misconduct.

The problem of the relations between the activities of scientists and the media has grown to new dimensions with the setting up of departments of communication attached to research institutes or laboratories. These departments can contribute a great deal to ensuring that the scientific information transmitted is of a high standard. However, insofar as they use techniques of communication based on effective promotion, there is a risk that the information will be biased in its choice or presentation. This problem is not only connected with individual behaviour but also with institutional policy.

To this must be added the role that risk capital companies are starting to play. These companies are being set up by biologists to exploit their discoveries themselves, which means that financial interests are directly involved in scientific information. On a different level, the success of appeals by the media to public generosity in order to collect plentiful funds for medical research projects involves serious risks of misinformation in addition to its beneficial effects.

The oversimplified image of pure information produced by research but "polluted" by the media is therefore increasingly contradicted by impartial observation of the real situation. Today, the responsibility of the scientific community is involved in ensuring the high

standard of biological and medical information, and this is now a very important factor in solving the problems at issue.

As regards the media, they are anxious to form their own opinion as far as possible, and to this end have developed, in the field of research, investigative journalism which today is an influential and in principle beneficial form of scientific information. However, the changes in the world of the press, in an age of universal communication and financial profits, are having strong effects, especially at a time when the media are looking for ways of increasing their audience by a constant quest for scoops, and leanings towards the sensational and emotional. All this means that the reliability and honesty of scientific information are very often sorely tried by the ways in which it is presented and headlined, and even by a certain lack of rigour as regards persons and facts.

Such deviations encounter all the fewer obstacles as the number of qualified scientific journalists in France is extremely small, which makes it hard for them to keep up with the ever-increasing complexity of highly specialized disciplines. In addition, they have to contend with the economic and financial pressures exerted on them and their press organs by large public or private concerns. Too often, medical information is simply a front for publicity. And even the reference organs constituted by the most reputed but non-specialized scientific journals are starting to be affected by the logic that governs communication by the media.

Certainly, in the swelling flow of information on biological and medical research, these disquieting facts are fortunately still far from characterizing all press organs and all the questions treated to the same degree, but they are already far more frequent than the exception that confirms the rule.

## **An ethical concern that calls for the sharing of responsibilities**

Because the French National Consultative Ethics Committee was worried by this state of affairs, it decided to tackle the problem itself, thus undertaking a task whose provisional results were set out in a report submitted to public debate in December 1994, during the days annually devoted to public discussion of ethical matters. The various reactions the Committee has recorded, both on that occasion and since, prompted it to extend its reflection in order to state its opinion on controversial points and complete the original report with new indications. This extension was the subject of a supplement to the report. Meanwhile, the Committee has been asked for an opinion on this question by the Ministry of Research, and the present opinion constitutes a reply to this request.

For our Committee, this opinion is at the same time more and less than the first guidelines of a deontology. Less, because the Committee is in no way entitled to intervene in determining the particular duties of the professions concerned, and will therefore limit its discussion to the general aspects of the ideas and initiatives it considers desirable. More, insofar as ethics goes further than the framework of any deontology and necessarily includes concern for all aspects of social life. This should not in any way lead to the underestimation of the value of documents like the Journalist's Charter, drafted in France in 1918 by the National Union of Journalists, of the present attempts to update and complete this Charter, or of the efforts undertaken by the scientific community to draw up codes of good conduct for researchers. But where else can deontology find its ultimate sources of inspiration and the guarantees for its application than in a common will to ban dishonest practices, and in the ethical requirements which sustain that will ?

The basic principle behind these proposals is not in any way specific to scientific information : it reminds us that to inform people correctly is an end in itself. And it is treating people simply as means, if the choice of subjects about which to inform them and the ways of doing this are subordinated to considerations which have nothing to do with the high

standard and honesty of this information. It is not the ethical requirements of transmitting scientific information which are specific, but the situation motivating this transmission, i.e. the power conferred by scientific competence on those who do not possess it, and the abuses of power that this inequality makes possible. Here the word "manipulation" exactly defines the fundamental lack of respect for people in the many ways in which in the transmission of information, they are treated like objects.

The solution certainly does not involve exerting outside control on scientific information and thus infringing freedom of the press and the independence of journalists. However, to replace the disquieting possibility of such control by a system of self-censorship, solely based on the individual responsibility of each of the participants, would be to underestimate the social dimensions which the problem has now acquired. The best way of ensuring that the present situation will develop favourably would be the expression of a common will on the part of the two communities most directly concerned - the worlds of science and the media - to organize independent exchanges of experience and points of view, and work out together the appropriate actions and measures. Such cooperation would gain much from including the citizens in suitable ways and at suitable times, with the aim of progressing, as far as possible, from information that is conceded to information that is more widely shared. For it should not be forgotten that in the last resort, the whole of democratic society is concerned by the present powerful acceleration in the advance of science.

## **Recommandations and suggestions**

These general considerations are anchored in a whole series of concrete questions which our brief remarks cannot claim to exhaust and which concern either the scientific community (points 1 to 4) or the media (points 5 to 8) or both, or more generally, the national community itself (points 9 to 13).

### 1. chronological sequences to be observed when transmitting information

The transmission of sound scientific information has its own chronology. The essential requirement in this respect is for a result of research to be published first in a scientific journal with a readers' committee, which ensures as far as possible that it is reliably evaluated. The practice according to which a researcher contacts the media directly to inform them of a result and avoids submitting it to the imperative prior evaluation by peer review can only, in general, be condemned. In addition, there is an order of priority to observe among the various recipients of any news item with practical implications. Thus, it is not right to inform the general public of a therapeutic innovation before informing physicians and those responsible for public health, as this can create very harmful situations. On the other hand, it is unacceptable for a researcher or research team to block the disclosure of a discovery in order to have time to profit from it, thus treating scientific knowledge as private property.

### 2. incitement to publish : a system that needs reconsidering

The institutional logic that pressures researchers into publishing at any price generates bad practices, by making the number of articles published virtually the sole criterion for the evaluation of work and the allocation of means. This concerns the quality of scientific information at its source. The problem is longstanding and its solution is difficult. However, one can only hope that the undesirable effects of the system will be reconsidered wherever they are observed, and that more value will be attached to other important criteria of the activities involved in research, including the part played by scientists in initiatives designed for the diffusion of knowledge. It is also important for scientific institutions to require the transmission of all the results of research, both positive and negative. Moreover, this requirement of total transmission casts a doubt on the ethical correctness of the partially

confidential clauses imposed on researchers by certain sources of finance, especially private ones.

### 3. revision of institutional communication policies

The setting up of public relations departments attached to laboratories and research institutes has fulfilled new needs and can greatly favour the correct understanding and transmission of scientific information. This is less true when these departments use techniques of communication which are derived from business competition and are designed above all for effective promotion, which is seldom compatible with the transmission of impartial information. The use of these techniques by public relations departments prompts researchers to use them too. Important scientific institutions, whose responsibilities are proportional to their prestige, can justifiably be expected to keep a watchful eye on this aspect of their communication policies and make sure that in all circumstances they set an example of the strictest probity.

### 4. action against complicity between researchers and the media

One invasive form of misconduct is the establishment of relations between professional scientists engaged in fundamental or clinical research and the media, relations in which the desirable climate of critical cooperation deteriorates into reciprocal favour granting. Thus, researchers sometimes have an understanding with journalists so that the latter will give prominence to their subjects or results of research without prior critical examination, and journalists may have a similar understanding with biologists and physicians enabling them to obtain unpublished information without any competition. Certain teams have gone as far as conniving with the media at launching campaigns designed to exert pressure on public opinion in order to influence financial policy makers in their favour, thus taking undue advantage of the various parties' lack of scientific experience. These practices make it opportune for the professions concerned to draw up codes of good conduct. The chances that such codes will be observed will increase if the public is itself correctly informed of the problem at issue and of the communal efforts made to solve it.

### 5. competence and instructional role of scientific journalists

The number of general and specialized scientific journalists in France is insufficient - about two hundred out of some twenty-eight thousand journalists. Leading organs of the media have no real scientific department, a situation doubtless not unconnected with the ample coverage they give the parasciences. This disquieting state of affairs leads to a chain of situations of dependence in relation to reputed sources of information, and to too many cases of flagrant misinformation. The question of the competence of scientific journalists is all the more serious as, although their function is not by nature to instruct, their activity is none the less liable to have a considerable impact, whether adverse or favourable, in this respect. Hence the great importance of training and recruiting a larger number of scientific journalists, as well as the reconsideration of their scientific news policy by the managements of the press organs and television channels concerned, and in a wider sense the attribution of greater importance to scientific culture and its requirements by the media as a whole.

### 6. responsibility of editorial bodies

In many cases, scientific misinformation does not reside -or resides little- in the content of the articles or oral statements of journalists, but in headlines and subtitles displaying various degrees of distortion, and in the lay-out and modes of presentation imposed by editorial boards, sometimes without the journalists' knowledge or even in the face of their disagreement. All these journalistic devices are known to constitute, as a rule, the essence

of the message received by the general public. The ethical responsibility of editorial boards is therefore all-important in this respect, and one can only support the efforts of journalists' associations to make known and put a stop to whatever in this domain may constitute an abuse of power.

#### 7. equality of access to the media

There is not, in the field of science any more than in any other field, an infallible truth in whose name any norms of "good" information can be decreed. Consequently, responsible scientific information must be characterized by critical precautions that indicate its limits, and an open-mindedness that leaves room for contradiction. On the latter basis, it necessarily subscribes to the fundamental principle of equal access to the media. This explains the need to ban all exclusive rights and all privileges of access for individuals or sections of the scientific community, a need that highlights the importance, not only of the ethical scruples involved, but of the journalist's scientific competence.

#### 8. correcting erroneous information

Although in science there is no absolute truth, there are errors which have been demonstrated. In addition, awareness of the relative nature of all information in no way dispenses from the duty of transmitting it accurately. In this dual sense, there is reason to raise the problem of correcting information whose formulation or interpretation is inaccurate, especially when this can have tiresome or serious practical consequences. Unfortunately, it is common to find that such corrections by the press organ responsible are late, incomplete and not prominently featured, and may be eluded altogether. This practice is shocking and in certain cases scandalous. That is why it is extremely desirable for the media themselves, together with the producers of biological and medical information, to work out the principles and modalities of measures to which those able to establish the erroneous character of an item of information or its interpretation can have recourse.

#### 9. resistance to economic and financial pressures

As biological and medical information can involve enormous economic interests, it is not immune to the commercial strategies of firms or industrial and financial groups who may find it advantageous to finance seminars, congresses, periodicals or specialized journals. Pressures which are often considerable are exerted on individuals. More generally, the increasingly important role of money is a factor that can be detrimental to the honesty and independence of information. It is therefore essential for scientific circles and the media to be made well aware of this serious problem, and this awareness should be supported by efforts to achieve financial transparency at all levels, and by the widespread disclosure of abusive practices. At the same time, the public must at all times be in a position to discern clearly whether information transmitted as scientific is authentically so, and whether or not its transmission is motivated by a desire for publicity.

#### 10. appeals to public generosity : the need for vigilance

Non profit making associations that appeal to public generosity to finance particular biological and medical research projects today play an important part in shaping the relations between the citizens and the world of science, and at the same time intervene in determining the priorities for research. The publicity and information campaigns organized by these associations, especially the television broadcasts which are their high spots as they jointly mobilize researchers, practitioners, journalists, personalities in show business, patients and their parents, play an exceptional role in transmitting scientific news, especially in fields which are highly charged emotionally, like those concerning cancer, AIDS and genetic diseases. It is therefore extremely important for the directors of these associations

and broadcasts to be constantly on their guard against the dangers of misinformation. There is indeed a risk that these dangers will be increased by the wish to achieve record fund collections, especially the danger of arousing false hopes about the period within which there is a reasonable hope of expecting effective new treatments, a period whose length can never be purely proportional to the size of the sums collected.

#### 11. the ethical aspect of professional training

All those undergoing professional training, both in research and the media, should be made aware during their training, of the ethical aspects of all these particular problems and the general considerations to which they point. Efforts to instil this ethical sense should be based less on the description of doctrines than on the study of cases showing the need for deeper, open-minded reflection and more fully informed acceptance of responsibilities. Such a possibility should also be available, as further education, to practising researchers and journalists. This aspect of professional training, designed for people not engaged in teaching, should at least include awareness of the pedagogical effects of all biological and medical news. These effects are extremely varied and require just as varied techniques of information, depending, for instance, on whether the news transmitted is likely to be reassuring or disquieting, whether it is aimed at well-informed or uninformed audiences, and whether it raises long-term or immediate problems.

#### 12. organisms for joint reflection and initiatives

As any hypothetical institution of the control of scientific information is considered unacceptable in principle, and as the necessary self-censorship on a purely individual level has proved insufficient in practice, any effort to solve the problems at issue can only be undertaken jointly by researchers and journalists. Organisms like the governing bodies and scientific committees of research institutes, editorial boards of press organs and radio and television broadcasting authorities can play a crucial role in initiating such joint efforts. A concrete form of such cooperation would be for the parties concerned to set up an independent authority with no legal powers but with moral prestige acknowledged by all concerned. Its task would be to develop an exchange of ideas and search for solutions to the problems posed by the present functional deficiencies. This proposal is aimed at favouring a widespread debate which ought to lead to the elaboration of original measures combining the preservation of freedom of the press and the independence of each individual with the responsibilities that this freedom and independence imply, especially in the extremely sensitive domain of biological and medical news.

#### 13. partnership with the citizens

Each news item creates a connection between its producers, transmitters and receivers. The first two categories -respectively scientists and journalists- obviously have very specific responsibilities in the treatment and solution of the problems this involves. An informer cannot be exempted from them on the grounds that the information transmitted is only a response to the public demand, as if this demand did not to a great extent depend on the supply itself. It would be a serious error to confine the role of the public in this connection to that of a falsely independent passive receiver, whereas in reality it should be the third active protagonist. For what is summarily referred to as " the public" is not a vague amorphous mass. The people who make up the public for scientific information of a biological and medical order are all the patients, their families, their associations and those who care for them ; all the youngsters of school age vitally concerned by scourges like drug addiction or AIDS, and their parents and teachers, and all participants in the great movements of social solidarity, from voluntary blood or organ donors to contributors to public appeals. In the last instance, these people include all the men and women who are witnessing the present prodigious strides in the knowledge and power of biology and medicine, and whose reaction is a variable mixture of admiring hopefulness and critical

anxiety. All these people should be constantly in the minds of those who produce and transmit the corresponding information, and it is together with them that producers and transmitters should play whatever part they can in the most varied training programmes, because it would be a hopeless task to inform a people with no scientific culture about life in the world of science. And efforts must be made to induce all of them to come together as partners in a collective endeavour in which ethics cannot be separated from democracy.

## Report

Scientific knowledge is growing increasingly fast. The means required to obtain it, and the economic and cultural interests at stake as a result of its social applications, are growing on a corresponding scale. To inform the public fully and honestly on the nature of achievements or projects in the field of scientific research is therefore more than ever a democratic necessity. However, the production of reliable information generated by events in that field, and its transmission to sections of the public which are often ill-prepared for it by communications media frequently governed by very different principles, is a task fraught with difficulties. In the field of biomedicine, these difficulties have now reached the point where there is cause for alarm from the ethical point of view.

It is of course true, in a sense, that the transmission of scientific information always comes up against the same problems, whether it concerns biological and medical research or any other field of knowledge. Nevertheless, the transmission of information concerning advances in biomedical research has important specific features, chiefly because it affects human beings and their health, and therefore the heart of human life and suffering involving the greatest fears and the highest hopes. This invests such transmission with a very high degree of responsibility.

The problem is a new one. Formerly, those engaged in medical practice and research were as secretive about their procedures as they were efficient in their treatments, and thought it natural to keep the layman uninformed. However, everything has changed in this regard, following the revolutions in treatment over the past fifty years and the breakthroughs in biology and genetics. Today, failure to disclose information in the medical field would be neither acceptable nor accepted. The intelligible, accurate and honest transmission of biomedical information to non-specialized sections of the public has become necessary for more than one reason. Because the research involved requires considerable collective financing from the public and private sectors, the judgement of experts regarding the scientific advantages and usefulness of a research programme must be such that it can be correctly understood by the economic and political policy makers and ultimately, in a democratic regime, by the national representatives controlled by the citizens. And when that research is liable to have both social and human effects whose moral acceptability is questionable, one of the elementary conditions of the ethical debate that becomes necessary is the availability of reliable, accurate information about the technical and scientific data underlying these effects. In addition, this information is a constant need for dispensers of medical prescriptions, a need also increasingly felt by the collective and individual users of new treatments. Among these users, such information, for better or for worse, is the object of constant protests, expectations and forms of behaviour which may have important consequences. This is why the need to ensure that this information is of the highest standard constitutes, in our view, a real social problem.

This problem seems to us in the first place to stem from the deep-seated lack of harmony between the situations, motives and procedures of the *three agents* indispensable to the process of informing : the scientists who produce the information, the media which transmit it and the different sectors of the public which receive it. For argument's sake, this makes it possible to distinguish three specific stages in the difficulties observed. However, they do not constitute separate successive stages along the one-way route of the information transmitted, because the public's active expectations and the demanding standards of the media inevitably exert their influence on the production of information by the scientists,



thus creating a tangle of supply and demand. An attempt to untangle these elements makes the objective importance of the difficulties encountered clearer, despite the often very subjective grievances that each of the three agents is tempted to have against the others.

The entire modern history of academic or lay representations of life and health has thus been characterized by controversies which all concerned the value of certain items of information. Some of them were theoretical, like the debate on the respective roles of the innate and the acquired in the human psyche, and others, practical, being concerned, for instance, with the effectiveness of a particular treatment. However, something that it seems legitimate to consider as an emerging crisis in biological and medical information has now been superimposed on this *structural problem* which is already causing a fair amount of concern : this crisis is manifested in many ways connected with the powerful trends henceforward at work both in the activities of the media and in those of science itself.

The hearings held by the working group in charge of this report have clearly shown us that this state of affairs is causing concern to increasing numbers of both research scientists and professional workers in the communications media. Critical studies are appearing and certain initiatives are taking shape. The National Consultative Ethics Committee does not labour under the delusion that it can reveal the true questions or supply the correct answers. However, because its working experience has made it extremely aware of these questions, its ethical task is to deal with them, and because the many different abilities of its constituent members enable it to have an overall view of these questions, the Committee wishes to make its opinion public, incite others to share its concern, and formulate proposals. Its aim in so doing is to promote the opening of a public debate and the invention of joint solutions in which the two fundamental freedoms, freedom of research and freedom of the press, will be more harmoniously combined with a concern for truth and a sense of responsibility.

## **I. A structural problem**

An attempt to define the general question of the relations between research, the transmission of information, and the public, within the framework of the question we are considering, is to embark on a process of reflection that is not without dangers, starting with the risk of being trapped into making spurious generalizations. For the general heading of research covers real and sometimes very important differences, for instance, between the bold opening up of a new line of research and the watchful verification of a result already obtained ; in the case of information, there is a similar difference between a news item published in a daily newspaper and an article in a specialized journal or even a chapter in a popular scientific publication, and between the press, and radio or television (9). In the latter media, there is also the difference between the direct and recorded broadcast, and the brief news item and magazine programme. Similarly, the term " the public" covers very different components, including scientists engaged in research, those responsible for health, and the community in general. These differences are so large that to handle such activities, types of information or persons without sufficient precaution is to risk intellectual confusion by reasoning according to entity, or even the moral error of amalgamating responsibilities.

Nevertheless, the banishing of all abusive generalizations cannot constitute a reason to abandon the very object of the proposed analysis, which is to grasp the mental processes and social procedures which in general are responsible for the extent and depth of the problem, and which underlie the errors and even the shortcomings that strike one at first sight and may illustrate the issues at stake.

### **Production of information by research scientists**

In the present world of science, the event which is usually decisive for the production of what will become scientific information is the publication by an individual or a team of the

results of their work. In the first place, this publication is intended for the community of scientists who are working on the same or a similar subject and might benefit from knowledge of these results. Its first objective is therefore not to transmit established facts to a lay public, but on the contrary, to submit to specialist criticism either new results of cases or experiments, or new theoretical considerations concerning experimental data which have either been acquired or which future experiments will make it possible to confirm or refute.

This is why the relevance and accuracy of all scientific texts submitted for publication are judged by a committee of readers, after they have been examined by a group of specialists in the field of research concerned. In general, it is by this type of publication that a research scientist obtains peer recognition, with all its consequences for his or her scientific and university career. Thus, for instance, it is generally the date of publication in a specialized journal with a reader's committee that constitutes proof of the possible anteriority of a discovery by an individual or a team.

However, the background to these publications is always the history of a discipline or a field of research in relation to which a discovery or theory is significant. In other words, the content of a scientific publication always forms part of the continuous work of the community of specialists that preceded the publication and made it possible, and that will follow it up by confirming or refuting it, totally or in part, in its concrete aspects or its interpretation. The content of such a publication cannot therefore be considered as factual information conveying truth in the factual sense. In particular, no narrowly circumstantial or theoretically ambitious interpretation of experimental results - and such results would be difficult to publish without any interpretation, if only implicit - can acquire any status other than that of a model allowing a fairly coherent representation of a certain class of processes at a given moment in the evolution of knowledge.

It is essential to have a full grasp of these characteristics to understand all that will follow. Scientific knowledge is in a constant state of development and only makes sense in its own context. Contrarily to what dogma aspires to be and to what is thought to be crude fact, this knowledge is not an absolute definitive characterization of its object. It does not claim to tell us, once and for all, what the reality is "in itself", even though its applications, for instance as regards treatments, may prove extremely effective in terms of mastering reality. Mistaken appreciation of the conditions attending the production of scientific knowledge, and all misconceptions as to the nature of the truth it conveys, constitute fundamental distortions of its significance and scope. These distortions are the source of a whole group of difficulties which affect the entire process of transmitting biological and medical information to the general public.

The production of information intended for the scientific community is governed by its own laws, imposed by the objective of jointly building up a body of evolutive knowledge consisting of theoretical models and technological know-how. These laws are certainly not perfect. They favour research whose results are to be expected within the framework of recognized models, rather than deep-seated innovations liable to upset established concepts. Judgement by peers is not immune to the effects of a school of thought, struggles for influence, or authoritative arguments, as shown by an instructive experiment on the fate of articles by eminent authors which had already appeared in very demanding scientific publications as the work of unknown authors. The result was that in some cases, their value was not acknowledged by the same readers' committees, which rejected them as inadequate.

Moreover, for lack of appropriate historical and philosophical training, a number of research workers in biology and medicine find it hard to put their own work in perspective and assign it the right place in the long-term evolution of knowledge. In this connection, the references cited in scientific publications do not, on an average, go back further than five or six years (10), and certain specialized journals even refuse to publish references going back more than two years, a trend which promotes the organization of a disconcerting absence of historical memory. It nevertheless remains true that this system of granting recognition of

scientific work by publication in journals with an international committee of readers has the great merit of having instituted a universal mode of scientific thought capable of self-criticism down to its very foundations via a process of communication that transcends cultural barriers.

However, the imperfections of the system are the source of another group of difficulties. It obviously does not guarantee that a discovery of major importance will not, for a time, go unrecognized, or that conversely, everything that is published is important and reliable -not to mention deliberate frauds, to which we shall refer later. The temptation to break away from the rules of the system therefore exists for both scientists and the media. The image of the innovating research scientist who is in advance of his time, and because of this, is not recognized by "official science" always has a certain appeal. Often, it serves to justify all kinds of "off-beat" theories or techniques, some of them hare-brained or even quite unacceptable in the empirical and logical framework of scientific practice; these theories and techniques seek to obtain "wild-cat" recognition, and exploit the intrinsic incompleteness of scientific knowledge in order to disregard its most reliable criteria.

This is more especially the method adopted by the parasciences, appropriately named because they imitate the exterior forms of scientific research without understanding its spirit or conforming to its requirements. This method is supported in varying degrees by certain general information sections of the press and is favoured by the cleavage between "scientists" and "non-scientists" produced by our educational system, and even by certain deficiencies in scientific training itself. In the liberties taken with the strict rules of science lies the primary source of the usual distortions to which scientific information becomes subject when it leaves the sphere of the community of experts and is appropriated by the media to be turned into news. What is more, as we shall see later, such liberties are increasingly taken by research workers themselves, in ways and for reasons which are partly new and can have very harmful consequences. That is why the oversimplified image of pure undistorted information produced by the scientific community being "polluted" by the media is increasingly disproved by impartial observation of the real situation.

### **Transmission of scientific information by the media**

On the basis of its production in the form of a specialized publication, scientific information is taken over by the media and transmitted as articles in the press or audiovisual programmes. This involves one of the far-reaching and difficult problems : the choice, from among the mass of scientific reports continuously published, of those to be explained to the readers, listeners and viewers on the receiving end of each news medium, and of the way in which these reports should be presented.

The general information press is indeed under certain constraints, and sometimes pursues objectives which are not easy to reconcile with the demands of accuracy, objectivity and critical caution which are inseparable from the production of scientific information. Thus, the criteria according to which this press decides that an item of information constitutes interesting important news which should be widely circulated, and decides how to do it, are very different from the criteria on the basis of which the value of a scientific investigation should be appreciated in the context in which it was carried out.

### **Accessibility of information**

One criterion which is in a way a preliminary to the choice of scientific news items by the media is their degree of intellectual accessibility, as evaluated by the men and women responsible for their transmission. This accessibility obviously depends on the nature of the scientific discovery itself, the technical difficulties of explaining it and the conceptual and linguistic obstacles to its being generally understood. But at the same time, it is related to the level of biological and medical culture of the journalists dealing with a discovery. The complexity of present-day biomedicine has in many fields become so great that even

specialized journalists may have difficulty in mastering it and reporting new developments without distortions. And it is not uncommon for journalists responsible for circulating biological and medical news to have no scientific training which would enable them to consult specialized scientific publications directly and judge their contents for themselves. This state of affairs not only increases the risk of incorrect transmission but helps to concentrate the power of choosing and evaluating scientific news in the hands of a few journalists known for their competence in scientific matters, especially when they work for highly respected publications.

This constitutes an important specific feature of scientific and technical information compared to the other kinds that make up journalistic news. The content of general items of information can on the whole be understood and appreciated by all the members of an editorial team, who can therefore judge the importance of each item and the suitability of making a choice between them. However, the content of a scientific or technical news item, like the context of the discovery it discloses, can often only be understood and appreciated by specialized journalists. Their position in an editorial team is therefore very different from that of their colleagues who are not specialists in scientific news, because their work is inevitably less dependent on the team's collective choice. For the same reason, scientific news items are often imitated or amplified : one or two newspapers set the tone, and are followed by most of the other audiovisual or press organs. It can therefore happen that the subject of an article chosen by a specialized journalist for questionable reasons, or an incorrectly presented (11) scientific advance, is unanimously reproduced and recirculated by the media, without any criticism, or even necessary rectification, being possible, at least with as wide a circulation as the original news item. When, for instance, the item concerns the effectiveness or ineffectiveness of a medical drug or therapy essential to the treatment of a serious widespread disease, this conceivably poses a major problem of news ethics in relation to society as a whole.

One question constantly linked to the concern for accessibility is that of language. Terms like gene, enzyme or metabolism, which are already in general use, have in reality a technical meaning which is not simple and moreover varies depending on the context. To an even greater degree, words like nucleotide or blastocyst, and expressions like "susceptibility gene" or "cellular differentiation" only conjure up very vague notions to most readers or television viewers, whereas others like "genetic manipulation" or "embryo" are liable to give rise to extremely regrettable confusion, for lack of rigorous scientific criticism of the reports concerned. Take, for instance, the number of debates on the embryo which are introduced without any valid explanation of what should be understood by "embryo" at the time of fertilization, or of how it develops in the weeks that follow. In a wider sense, the tendency to define the diversity of certain processes by the use of general terms such as "alcoholism" , "drugs" , "eugenism" , etc., terms liable to be understood as denoting "persons in themselves" , constitutes a formidable intellectual trap, by substituting the manipulation of fictitious entities for the analysis of concrete realities.

In an effort to be intelligible, which in itself is praiseworthy, most journalists use technical terms as little as possible, although they are not always happy about the choice of terms they prefer to use. This results too often in considerable boiling down of scientific information and sometimes even complete falsification compared to the original article in a specialized journal. It may even happen that the media prefer to use an expression which is assumed to convey more but is in fact misleading, to an expression that is scientifically correct and can be understood by everybody. Thus, shortly after it was set up, the National Consultative Ethics Committee repeatedly explained to journalists that the women they -and also others- called "child carriers" are in reality "donors" , and in most cases "vendors" , of a child that they do not simply "carry" for a period of gestation but which was procreated from their own ovocyte and is therefore biologically theirs. Because the expression "child carrier" suggests that this simply involves the "loan of a uterus" whereas in reality it involves the transfer of a child, it blinds the general public to the nature of the very serious ethical problem posed. In spite of this, certain journalists have continued to use this expression, which is clearly incorrect. These remarks also concern the use of the word

bioethics, which runs a serious risk of implying that the vast problems it designates are simply a branch of biology like biochemistry or biophysics, or even the special prerogative of professional " bioethicians" . It is therefore important to stress the very far from neutral nature of questions that concern vocabulary.

#### Choice of the information

As a rule, the news items the media choose to transmit from among those that seem accessible to the layman (provided their choice is not predetermined by the scientists, of which more later) are above all selected for their potential interest to the public, such as the editorial staff responsible conceive or even wish that interest to be. Thus, certain subjects are considered *a priori* to be of greater interest than others, for four possible reasons : they concern diseases feared by a large section of society, such as cancer or AIDS; they seem to constitute an evolution in the usual conception of the life process, they allow people to dream, in the same way as science fiction, or they may affect the most widely held philosophical or religious convictions, as in the case of subjects like the relation between the genomic inventory and " human nature" , knowledge of the brain and the concept of consciousness or the evolution of species and the origin of humanity.

The personalities in a team of scientists, or the individual scientist's attitude, also help to transform a piece of scientific news into a headline story. The renown or the responsible position of certain scientists means that any account of their research or statement on their part come to be considered as events in themselves, which is far from always being justified. The nationality of a scientist or of a team also plays a part in the choice of news transmitted, according to whether or not one should give precedence to one's own country's research, a tendency that some consider natural and others, chauvinistic. This grading of the importance of biological and medical news items, which in varying degrees is substantiated by objective considerations -be they theoretical, cultural or concerned with health- is almost always ultimately made to look justified by the presumed interest of the public. However, on closer examination, this notion is obviously dangerous. It is true that this interest can be estimated from the degree of success (i.e. the number of copies sold or numbers of viewers and listeners) encountered by the repeated dissemination of news about a given subject. In this sense, journalistic activity responds to a pre-existing demand by the public receiving the information, and can be considered as a form of the expression of public opinion as well as a means of transmitting information about scientific events. The considerable increase in the French population's interest in medical matters during the last twenty or thirty years lends importance to this view.

However, the constantly confirmed observation that the media shape public opinion at least as much as they express it, is particularly relevant to scientific and technical information. For if non-specialized journalists find it hard to evaluate the relative importance of scientific news items, this applies at least as much to the general public. What real share can it have as a function of its curiosity and expectations in the choice by the media of the items that are transmitted and those that are not ? In particular, there is the risk that what is assumed to interest the public is in certain cases rather a reflection of the preconceived ideas fostered about and among the public than the result of balanced judgement. This is typically the case for the important place or distinctly favourable treatment which the media too often give to the parasciences or even to medical charlatanism in the field of biomedical news. We feel it is useful to state once again here what should be obvious -that the power of choice involves the duty of responsibility.

#### quality of news transmission

The choice of a piece of research for diffusion by a non-specialized publication in the press makes it a news item. This is then transmitted as an account of an event, accompanied by a variously detailed commentary, and an evaluation.

To *recount an event* as early as possible after its occurrence is one of the traditionally primordial requirements of journalism. Information thus becomes news through competition to be the first to publish it, especially for items considered to be most important or even sensational. This striving for a scoop is far from being exclusively practised by journalists. The time necessary for reflection and for any verifications necessary to validate information by placing it in its context is often sacrificed to the interests of rapidity. It is indeed hard to reconcile the conflicting demands of scientific exactitude and those of the "news value" required by the daily press and to an even greater extent by radio and television. The form and pace of news circulation help to establish the "priority of rapidity over responsibility, (...), of emotion over thought, of the spectacular over the demonstrative and of the reflex over relection" . (12)

Weekly or monthly periodicals, radio and television news magazines, and the educational scientific press -still too limited in France- are fortunately, in various degrees, a little less bound by the need for speed. Consequently, the best of them not only make a positive contribution to news but help to create a well-informed readership by transmitting authentic information. However, even at this level, the reporting of too many subjects in the magazines, and too many television broadcasts on biomedical topics, still sacrifice sobriety to the more facile striking phrase, instantaneous emotion or spectacular development, while at the same time expecting qualified guest writers to express themselves in 30 lines or even 30 seconds on extremely complex questions. To take another example, when the editor of an important weekly considers that to "sell" science to the public, it must be presented "like a theatre or film script, constructed according to the principles of good, evil, conflict, struggle, victory or defeat" (13) , one may justifiably wonder how far this conception of scientific news is not also closely connected with its distortion, for science implies cooperation at least as much as competition, and the rejection of manichean dogmatism in favour of critical exchanges.

The *commentary* that accompanies the recounting of an event acquires even greater importance when the subject is the communication of the result of a work of research. For as we indicated at the outset, one of the essential characteristics of scientific information in general and biomedical information in particular is that it cannot be validly transmitted as the narration of a factual event; for it only makes sense insofar as both the content and context of the research work involved are explained and its scope is made clear from the practical and theoretical points of view, as illustrated by its potential biological and medical applications and the various kinds of problems it raises -in particular ethical problems.

The problem of how to present statistical results deserves special mention here. Why has a particular criterion been used to judge one result as being better than another ? On what type of sample was this result obtained ? What were the conditions of its validation ? These are the details that the research scientist must supply, and on which the journalist in turn must comment, in order to avoid gross distortion and over-hasty interpretation. For all this, a special type of training in news transmission needs to be invented. The mastery of a few basic principles and notions of statistics has in fact become one of the conditions for the exercise of responsible citizenship. Otherwise, there is a risk that the most questionable polls or least justified percentages will be considered completely credible. (14)

In addition to the transmission of news in itself, there is the need for a real effort to educate the public in the realm of the research in question. Even if such education is necessarily superficial, there are a few good examples to demonstrate its feasibility. It seems to us that this is an important factor in the ethics of scientific journalism. Many scientific journalists who are ill-prepared for such an educational role, reject it together with the responsibility it implies, on the basis of the traditional argument according to which the profession of journalist is exclusively the transmission of information, whereas it is now common knowledge that the media today play an important part in the initial training of youth and the adult education of the general public. This, we believe, is one of the main problems at present concerning biomedical information, and joint efforts to think about its solution by research scientists and specialized journalists should prove very productive.

On condition, of course, that editorial boards and television channel managements are really determined to solve it. In certain cases, one has the impression that this is not so. Some publications in the press seem to take pleasure in spreading a type of culture for the masses in which pseudo-scientific biomedical jargon covers a host of spurious ideas and superstitious beliefs. Readers treated in this way can no longer, for instance, fathom the gulf that lies between the announcement that certain types of cancer can be cured by gene therapy, and the promise that a surgical operation carried out under favourable astrological conditions will succeed or that the opposition to such a promise is only based on an obscure power struggle in which both parties are equally to blame. Attempts to justify this by the public taste for light entertainment or gratifying illusions is, in the present case, tantamount to frivolously disclaiming any guilt for something akin to the fostering of infantilism.

Contrarily to the news commentary, news *evaluation* is a task that journalists are all the less inclined to shirk as it constitutes the essential part of what can be considered as their power. For such evaluation not only involves transmitting and commenting on the content of a news item concerning research, but also estimating its value and importance in the history of the scientific field under consideration, both in relation to the work of other competing teams in France and elsewhere, and from the point of view of its application and possible repercussions on society, public health and even our vision of the world and philosophy of life. Under these conditions, the journalist may be strongly tempted, either to leave this responsible task to others by repeating what other scientific or news commentators have already said, or else to use the function of evaluation as an instrument of power. And this raises news kinds of problems which now have to be examined.

### **How the public perceives scientific news. Feed-back effects and their problems. ofdes ideologies**

After disclosure by the scientists and transmission by the media, scientific news eventually reaches the *public*. This third stage in its journey is not only the terminus, but -it must be borne in mind- the initial aim. News is only effective once it has been conveyed; it is not a thing, but a relationship, and in that relationship, the public is not, and should not be, a less important protagonist than the scientists and the media. Too often, it seems to be considered passive and therefore inferior. Perhaps that is just where the deepest fault lies in a certain conception of news.

To take the public seriously means first of all to stop referring to it in the singular. Scientific news, like general news, does not have a single public, but different audiences with enormously different levels of knowledge and culture, as well as interests. The very diverse vehicles of scientific information endeavour to cater for these differences, as they range from general news organs to extremely specialized publications, for which the difficulties referred to above intensify considerably in degree, but their nature does not necessarily change.

All audiences grasp scientific information across the spectrum of their knowledge and ignorance, and of their culture or lack of it. In the case of what is known as the general public, the question of how this information is received is especially vital. It is regrettable that the standard of this reception has not, so far, been the subject of many works of evaluation in France, as such studies would enlighten and provide food for thought for both journalists and scientists, who are not resigned to the spread of the mass pseudo-scientific culture described above. (15) The chronic insufficiency of regular scientific programmes of a good standard on most French television channels is partly responsible for this situation.(16) The diversity of the general magazines whose editors undertake the task of popularizing the world of research and the social repercussions of science proves the existence, in France as elsewhere, of a vast public intensely interested in this field and eager for information concerning it.

Once the complacent attitude has been overcome according to which the lack of scientific

culture among the vast majority is a natural necessity, for which responsibility is even imputed to the men and women who are in fact rather its victims, it becomes clear that even misunderstanding of the questions asked or their apparent ingenuousness -whether, for instance, the cow is one of man's ancestors, or whether one can catch the AIDS virus by kissing on the mouth- reveal trains of thought which are by no means irrelevant.

Many of those for whom scientific news is intended are in reality -as far as the means available to them permit- far from being merely passive and ignorant. They do have knowledge and ideas about scientific work, derived either from what they have been taught or from reading, as well as experience of biomedical reality, acquired from being a patient or from conversations on the subject with those around them. They have legitimate expectations, shrewd questions, and very often, persistent dissatisfaction with the way in which biological and medical information is currently transmitted. Thus, there is a growing number of educational initiatives in schools, of direct meetings between biologists and physicians, and of efforts by patients' associations to remedy the inadequacy of the information available. These attempts are not all free of the new risks involved in conveying erroneous information. Nevertheless, conditions are emerging which would make it possible to progress from information that is dispensed, to information that is genuinely shared, through the collective invention of new forms of interactivity. We believe that this constitutes a promising course of action which should be more boldly pursued in order to turn an audience of citizens into an active partner in promoting the necessary mass scientific culture.

These *feedback effects*, which are still insufficiently developed between the different audiences on the one hand, and producers and journalists on the other, are on the contrary, one of the main features of the relations between the world of research and that of the media. Because the leading research institutions are conscious of the objective difficulties inherent in converting scientific information into news and are often dissatisfied with the result, they are now in the habit of using the public relations services attached to their organization. These services are responsible for informing the chief organs of the press about the research conducted in their institutions, thus facilitating the work of the journalists, including their commentaries and evaluations. In their role of intermediary between research and the media, these public relations services use the usual techniques of the communiqué or news conference, or else communicate directly with individual journalists or news agencies. This means that a logic of promotion somewhat interferes with the needs of scientific communication strictly speaking. The weight carried by the information these services communicate, which is already in summarized and simplified form, is all the greater as the journalists on the receiving end are themselves less well equipped to judge the content of a specialized scientific article.

While the use of a public department helps to solve some of the problems mentioned above, it does at the same time create other problems. It has the virtue of helping journalists to improve the accuracy of the information they impart and the pertinence of their comments or even of their evaluations, while helping researchers to clarify their ideas about the imperative needs of accessibility and the conditions of effective transmission. However, this interpenetration of roles also favours their reversal or even their distortion, because it tends to allow the penetration into the realm of research, of journalistic practices such as oversimplification, a search for the sensational, the dramatic impact of the announcement, and the use of the media for promotional ends. One could even go as far as to say that what constitutes a piece of news is the press conference or statement to the media, independently of its scientific content or degree of truthfulness, especially when well-known scientists are involved. In this way a type of relationship is created between the journalist and the researcher in which the indispensable climate of criticism may degenerate into mutual favour granting. Some journalists may make use of certain researchers to enable them to be the first to publish good news items and thus consolidate their personal status in the profession. In return, certain researchers may use the journalists to give prominence to their subjects or results, with the dual aim of exerting pressure on the public and those who decide policy, in order to acquire greater credit for their work and thus strengthen their



power in the scientific community. All this perverts the logic governing the production of scientific information, and the recent development of such forms of behaviour constitutes one of the chief sources of the emerging crisis which we shall attempt to analyse further on.

### **The role of ideologies**

These feedback effects between the actors on the scene of scientific news transmission are all subject to a far more widespread process which may have more serious consequences. As we have seen, scientific information is liable to have a marked effect on collective conceptions and beliefs, on visions of the world and of society with their underlying systems of values, in short, on ideologies in the widest sense. However, ideologies are not in themselves passive inert forms of consciousness but are part and parcel of practical and symbolic activities ; they federate interests, galvanize passions, permeate institutions and sometimes become official through State action. Consequently, their reaction to scientific news is often biased and is aimed at either confirming or refuting it. In extreme cases, as history has often shown, ideologies turn some items of information into dogma and declare war on others.

The Lyssenko case is still the classic example of this. As, in the USSR of the middle of this century, " Mendel-Morgan genetics" were considered incompatible with Party and State philosophy, they were totally censored for nearly twenty years, with disastrous consequences in many fields. In a social and political environment that was totally different but strongly characterized by the ideology of the innate inequality of individual intelligence and the corresponding practices of selective school entry, the British psychologist Cyril Burt propounded as an indisputable truth for generations, the universally adopted thesis according to which intelligence, assumed to be measurable, is determined " 80% by heredity and 20% by environment" . He based this conclusion on his famous investigations of true twins, which are patently fraudulent and whose very principle is fundamentally unsound.(17)

Ideologies thus emerge as very powerful selective distorting factors in the transmission of scientific news, the more so as they bias the judgement, not only of the public but also of journalists, and even in large measure that of many scientists -who are sometimes unaware of this; however, unconsciously instilled ideologies are not the least insidious. For instance, the scientific information transmitted about genetics is today strongly affected by ideologies. An example of this is the concept of " mankind's genetic inheritance" , which by interpreting literally a metaphor of oversimplification taken from computer software, tends to underestimate or even not to realize the importance of epigenesis, and more especially, when human beings are concerned, of their social and cultural background.

The uncritical acceptance of such ideologies leads to a fair number of distortions in the choice, comments and evaluations concerning the biological news items transmitted, and perhaps in the scientific work itself from which they originate. That is what leads to the regular reappearance of items according to which " the" gene governing some of the most complex human functions or mental attitudes, such as intelligence, criminality or altruism, has been discovered or is on the point of discovery. Such statements are based on work in which the observation of variously close statistical correlations is often confused with the establishment of causal relations having the value of a demonstration. (18)One point to make is that strictly speaking, the only certain conclusion one can draw from the search for a correlation is negative : if one can state that there is no statistically significant correlation between X and Y, then X is certainly not the cause of Y. At the same time, there is the serious difficulty that one can never state with absolute certainty that a relationship does not exist. Thus, a non significant correlation between X and Y, established on a sample according to given procedures, could become significant on a larger sample, using better constructed experimental or investigational protocols. This is why the cautious researcher will say that " According to present knowledge, there is nothing that allows us to state that there is a correlation between X and Y" .

When a significant correlation is established, its interpretation is never simple. First of all, a correlation does not indicate the direction of a possible causal relationship : is X the cause or the effect of Y ? For instance, if the percentage of patients among the persons leaving a physician's consultation is significantly higher than in the general population, it is not correct to conclude that visiting the doctor is a cause of illness. Nevertheless, such erroneous reasoning is far from rare. One instructive example is that of Diethylstilbestrol, a synthetic oestrogen which in the middle of this century was widely prescribed to avoid spontaneous abortions. On the basis of the observation according to which women who had had such abortions produced fewer oestrogens than the others, it was overhastily concluded that oestrogen deficiency was the cause of the abortion, and it took several years for doctors to realize that this treatment was ineffective and could even cause serious harm to girls born of mothers treated with Diethylstilbestrol. Later, the reduced oestrogen production was found to be an effect of the abortion and not its cause. To avoid such errors, there should have been a prospective survey of a very large sample of women producing fewer oestrogens than normal, whose abortion rate should have been compared to that of a control population. However, such studies are long and difficult, and the reverse retrospective study was chosen. This was easier but insufficient, and proceeded from the presumed effect (abortion) to its hypothetical hormonal cause.

The latter procedure is common, as it is usually much more convenient to test a causal hypothesis by proceeding from the effect observed to its assumed cause than to proceed conversely, from a cause to its presumed effect. It is easy to understand how very hypothetical the conclusions drawn must remain, in the absence of subsequent verification. In addition, this method gives scope for the fallacious procedure of highlighting a secondary or even an artificially isolated factor, because that was the one chosen for testing, for various reasons connected with fashions or an ideology.

Another aspect of the difficulty lies in the fact that X and Y are mostly linked to a host of factors which might include a cause of Y. There are countless examples of this : for instance, the assertion that bronchial cancer affects more men than women, not because of a genetic difference but because men smoke more. Statistical techniques allow such " third factors" to be taken into account, i.e. the testing of the relationship observed between X and Y to see if it can be explained by other definite factors. However, these factors do not exhaust the infinite number of possible unidentified factors, so that no single observational survey can enable conclusions to be drawn about causality. When several factors are considered and their respective importance is estimated -as in the vexed question of how far a particular multifactorial character or behaviour is innate, and how far, acquired -an additive principle is often applied according to which each factor considered works independently. However, this convenient principle is rarely justified. It is all the less valid as the mechanisms of action of the factors considered are themselves little known, whether they consist of effects observed like complex forms of behaviour or multifactorial diseases, or of presumed causes like genetic markers, behaviour involving risks, or environmental factors. It is not, for example, sufficient to identify an infectious agent among subjects with a given disease in order to state that this agent is responsible for the disease. The observation that its frequency is high among patients does not constitute a proof of its pathogenic power. To supply such proof, its mechanism of action and transmission must be studied, and among other points, the frequency of its presence among healthy subjects. Only then will it be possible to conclude that this agent is, or is not, the cause of the disease, and if it is, that it is the total or partial cause. It is also on the basis of over-hasty interpretation of correlations that particular types of food are often held to be responsible for causing serious harm, or else are endowed with preventive powers.

Unfortunately, it too often happens -especially when a researcher is anxious to be first to publish a result- that conclusions are already drawn from or at least suggested by initial observations, in the absence of any confirmation by the discovery of determinant mechanisms.

Another category of examples concerns the diagnostic value of new tests and techniques of

examination. After the discovery ten years ago of the extraordinary achievements of magnetic resonance imagery (MRI), this technique has only been validated and used by correlating abnormal images with various pathologies. Only recently have systematic studies been undertaken of the sometimes high frequency of misleadingly abnormal images recorded in the absence of any pathology (false positives). Such studies are indispensable to avoid the deviation that consists of treating images -and more generally the results of tests- rather than pathologies.

Underlying all these difficulties, a vaster epistemological and philosophical question is taking shape : what is a cause ? A " weak" pragmatic definition could be following : X is a or the cause of Y, if a change in X leads to a change in Y, when that change is assessed according to the usual methods of experimental research. According to this definition , the purchase of a lottery ticket is a cause of gain, because it is the buyer's only way of winning. This is the idea behind the advertising slogan " 100% of the winners had tried their luck." . Note that a change in X can lead to a change in another X factor which might be the real cause. It is therefore necessary to give a " strong" definition of causality : X cannot rightly be considered a or the cause of Y unless, going further than the statistical study of their correlation, it has been possible to reveal the mechanisms by which X produces, or helps to produce, the Y effect. At this point, the notion of cause moves onto the theoretical ground of explanation, and therefore of the understanding of processes.

This philosophical debate on the notion of causality is not new, but today takes on new forms, and will certainly continue in the future. This does not prevent those with experience of the problems involved in the use of statistical methods from agreeing on the need for great vigilance, to avoid, among other things, the sources of confusion and errors of interpretation indicated in this note.

In July 1993, several press organs announced that an American researcher had just discovered " the gene of homosexuality" . Under this sensational headline, the actual content of the news item boiled down to the fact that the researcher in question had found an identical alteration in the chromosome X region of a few dozen homosexuals (19) . There is an enormous gulf between the two versions, as this limited unconfirmed observation in no way constitutes the identification of a gene, and nothing is known about how this hypothetical gene would " express itself" in a group of affects and types of behaviour as complex and socialized as those involved in homosexuality. Nevertheless, this news immediately led to the intensification, among a fair number of American homosexuals, of psychological attitudes and of the formulation of the problem of their social rights, and there is nothing to indicate that the results will not cause them harm. This typical example of ideological provocation by a scientific news item illustrates the very serious ethical problem involved. Its solution does not lie in the good but entirely utopian resolution to adopt an attitude free of all ideology, but perhaps requires personal effort to become more watchfully aware of the ideologies governing our thought processes. Certainly the solution also requires resolutely pluralist open-minded exchanges of critical points of view within and between the different sections of the public, the media and research scientists.

## **II. An emerging crisis**

The chronic and sometimes difficult problems we have just analysed are sufficient proof that the transmission of scientific information has never been as simple as is sometimes imagined. However, up till now, the recurrence of such problems did not affect the system described, which on the whole seemed able to cope with them, or at least not to be shaken by them. What is new today is that processes of unprecedented size or nature are displaying a powerful tendency to upset the system itself, as shown by the increasing and alarming number of cases where it fails to function.

The current electronic revolution heralds changes in the storage and communication of knowledge with far-reaching potential effects on scientific information. The communication

of electronic mail by international networks is starting to cause deep-seated changes in the way in which this information is transmitted and used. It tends to be propagated in a fragmentary way, without any verification, immediately after its production, in the form of electronic messages which can be consulted by anyone who has a computer connected to the diffusion network. This practice, which for the time being is less widespread in biology than, for instance, in physics, also seems destined to become general. It can be a source of unprecedented ease of communication between researchers working in the same discipline, enabling them to exchange ideas in the process of being forged, during "virtual" working meetings, even though they are thousands of kilometres apart. But at the same time, a new danger is emerging : the items of information thus transmitted may not be viewed by those who receive them in the right perspective, given their essentially provisional and by definition incomplete character. Another danger may be that they could be considered as indisputable pieces of factual information, quite separate from their interpretations, evaluations and concepts which might be published separately later in the scientific journals. If this type of cleavage became the general rule, there would be a great risk that it would undermine the very principle of scientific culture, already sorely tried by the exponential development of knowledge, and undermine society's capacity to deal with this development.

Other dangers, however, are more immediate : biomedical research, which is developing in many directions unprecedentedly fast, is demanding more and more resources and becoming involved in more and more large-scale or even gigantic financial and economic interests, which are revolutionizing the traditional criteria governing the dissemination of scientific news and the system by which it is produced and transmitted. The production of questionable scientific information by the world of research is arousing more critical attitudes on the part of the written and audiovisual press organs. But as they themselves are one of the means and ends which are essential to the competition for economic domination and political power, the media in turn help to destabilize or even distort the system of scientific news transmission. When all these factors are set in motion, the result is a rapidly evolving situation which is at the root of the ethical concern prompting the present report.

## **Scientific information and economic competition**

### scientific misconduct

A disinterested search for knowledge and altruistic striving for the good of humanity have doubtless never been the only motivations for scientific research. Like every other activity possessing social prestige, its underlying aspiration is to achieve celebrity and recognition, even by professional ambition and personal interest. However, until recently, biological and medical research in a country like France was greatly influenced by the traditions of disinterested humanism for which the name of Louis Pasteur is still a symbol. Today, however, the acquisition of new knowledge in molecular biology or the elaboration of new medical drugs thanks to genetic engineering require enormous sums of money or investments, and the markets and profits expected from these inventions are themselves colossal, which means that radical changes are taking place in the ethics of research. Thus, the race to achieve scientific and technological breakthroughs becomes more and more inseparable from the race for financial resources or profits, and biomedical information is tending, at least partly, to become one of the assets in this race.

It does seem that we are today living through the beginning of this disquieting mutation. It applies to the dangerous tendency of certain researchers to skip the stage of publication in a specialized journal with an editorial committee of experts, and straight away publish a fairly popularized version of their research in the general press, thus eluding the traditional test of peer review. When a leading American medical journal already pointed out this tendency in 1980, it linked the tendency with what it described as research of an extremely competitive kind, especially in a field like that of recombinant DNAs, which has an enormous commercial potential. Since then, the process has kept spreading, and the question asked

in the article just referred to is more topical than ever : how can journalists correctly evaluate research which has not been subjected to peer review ? (20)

In the race to capture the attention of the media, things go further still when teams of researchers launch real campaigns aimed at winning the support of public opinion in order to exert pressure for their benefit on those in charge of financial policy. This is how the first American project for total sequencing of the human genome was presented in a totally misleading way by representatives of the media throughout the world as at last making it possible to decode the " Book of Mankind" . This was done in order to influence the United States Senate, which was responsible for voting the gigantic sums necessary to finance what was claimed to be the new equivalent of the Apollo space project. Even after the genome project was abandoned in its initial form, it continued, in the public awareness, to bear the stamp of the original pretentious distortion. It would perhaps not be excessive to describe this as a case of transforming news into scientific misinformation.

Such deviations are considerably amplified when the media are involved, as they often act as an amplifier of what tend to look like veritable publicity stunts in favour of certain projects(21) . Even wrong information, knowingly published -i.e. scientific fraud-, is increasingly common. Unfortunately, fraud, the most radical violation of the ethics of scientific research, is of course not a novelty. What is new is that it is becoming less rare as the increasingly fierce competitive character of research and the scale of its conditions or economic and financial interests encourage personal failings. Fraud is also, and perhaps even more, the result of what here and there are proposed as " justifications" arising from the constraints imposed by this state of affairs (22) . A survey on this subject published in 1993 showed a disquieting evolution towards increasingly frequent forms of behaviour which it defined as " scientific misconduct" (23) . The concern for ethics is therefore truly justified.

#### Scientific knowledge and financial interests

Just as serious is the new tendency to treat scientific knowledge as a commercial commodity. The claim by American NIH researchers to be able to patent nude sequences of human DNA -i.e. sequences whose biological functions and possible applications are not yet known- is a recent example of major importance which has divided the international scientific community while disconcerting the general public. As the French National Consultative Ethics Committee said in its report of December 2nd, 1991, such a claim gives grounds, among other things, for the fear that " knowledge about the human genome could be appropriated for purposes of profit, " and that knowledge" could become a monopoly exclusively devoted to the development of biotechnologies" . These appropriations are comparable to the planting of a flag on unexplored territory." (24) If endorsed, they could initiate an unprecedented mutation of the status which has always been that of scientific knowledge, and would endanger the very principle of its free communication. The abandoning of this claim by those who made it was the result of a favourable balance of power within the scientific community, and also of pressure from public opinion resulting from the very ambiguous notion that " mankind's genetic inheritance" is by nature sacred. In that sense, the danger threatening the unappropriatable status of scientific knowledge cannot be considered to have been averted, and the reckless development of the identification of new genes -involved, for instance, in various types of cancer- gives reason to fear that the danger will grow.

More generally, the extension of the registration of industrial patents to the biomedical field, in accordance with patenting laws which differ markedly from one country to another, poses in itself serious problems for the transmission of the information concerned. Contrarily to what is generally believed, taking out a patent is far from being synonymous with complete disclosure of the knowledge concerned. First of all because the researcher or team to whom an advance in knowledge or technology is due might find it in their interest to defer applying for a patent for a long time. Secondly, because of the obligation of secrecy imposed on academic researchers by the firms financing their work, which means that the

disclosure is often incomplete (25) . Patents and secrecy may thus go together and strengthen various modalities of withholding knowledge which are prejudicial both to the development of research and to keeping the public informed. Conversely, the penetration of the profitability criterion into scientific research may favour over-hasty or even fraudulent publications, intended, for instance, to protect a firm in which scientists have an interest because they are involved in the research that preceded that firm's technological activity.

This last case is becoming all the more frequent as established biologists are fast setting up their own companies to commercialize their discoveries or reap some of the profits accruing to companies whose Stock Exchange quotation depends on the success or failure of a particular programme of research or development. This gives rise to the proliferation of conflicts of interest centering on support for research programmes, or on the publication of results on which depend both the confidence in the industrial or commercial success of a project and the Stock Exchange share quotation of the firm that has adopted that project. Things have gone so far that ethical questions are being asked about the impartiality of members sitting on the editorial committees of scientific journals of high standing. And here, the very heart of the scientific information system is implicated.

### **Scientific information and the power of the media**

institutional scientific information and investigative journalism

As a result of this situation, the traditional roles of science and journalism tend to be reversed, because more and more often, the media are not content to transmit the scientific information provided by the world of research but are anxious to form their own opinion, and so they undertake investigations on which, at least partly, they base the information they themselves produce.

The beginnings of this new trend can be seen in the conflicts that preceded the meeting held at Asilomar in 1974, which was supposed to produce a moratorium on the techniques for the recombination of DNA (known as genetic manipulations). It seems that for the first time, journalists wanted to take part in the debates as observers, and were not content to await an official or press communiqué. However, their wish was contrary to the scientific community's tradition by virtue of which only scientists can conduct a debate and pass judgement on the work of other scientists. This tradition, from which the practice of peer evaluation originated, had a tendency to spread beyond the scientific field proper and include the evaluation of research policies and even the ethics of scientific practice. This is why the appointment of a committee of enquiry on famous scientific frauds was not wholeheartedly supported by the President of the American Academy of Sciences, who questioned the wisdom of holding a public debate on the issue rather than relying on scientific institutions to check scientific findings and if necessary correct them.

The amplitude and acute nature of the social interests at stake in present day biomedical research, combined with the development of scientific misconduct, have seriously undermined the justification of the tradition referred to above, as regards its extension to scientific policy and ethics. The scientific community must agree to be governed by the principles of freedom of the press and the sovereignty of the citizens. In this respect it has come to resemble other communities of experts who are efficient but potentially dangerous, such as the army, whose traditions of total secrecy have had to start giving way to the democratic demands of free access to information. It is as if science, like war, which is too serious a matter to be left exclusively to the military, has become too serious a matter to be left exclusively to the scientists.

This tendency is being fostered by the growing interest in developments in biology and medicine on the part of the general public, which in many situations understands how greatly these developments can affect people's lives. Thus, the community of scientific specialists is no longer considered to be entitled to discuss scientific advances and take decisions regarding them behind locked doors. Even at the stage when knowledge is not yet

established and conclusions are hazardous, researchers are increasingly obliged to hold their debates with the information media looking on and listening, and are all the more bound to account for dramatic situations for which they may be in varying degrees responsible. This is why, for instance, international congresses on "hot" subjects like AIDS or cancer are now in the habit of admitting journalists, who transmit as news whatever information they can garner without waiting for the usual procedure of publication in a specialized journal. More than anything else, the increasing number of "affairs" which have stirred up public opinion has prompted investigative journalism to claim the right to act independently in relation to institutional scientific information (26) .

This essential role of acting as a counter-power, which a truly free press can play, can naturally be considered beneficial, although it would be an illusion to believe that freedom of the press is ever unlimited. Certainly, the system of State-approved information and censorship is to a great extent responsible for the fact that, for instance, nuclear tests involving the exposure of human beings to large doses of radioactivity could be conducted in the Soviet Union during the cold war. But it is worth noting that during the same period in the United States, the existence of a press whose freedom is legendary, in no way prevented human beings from being unconsciously subjected to experimental irradiation, nor did it prevent all information in this connection from being withheld for twenty years (27) . On the other hand, although as already indicated, the disclosure of all information concerning the evolution of science and its social effects is highly desirable, there should be equally strong concern about the tendency to substitute the evaluation of research work by the media for its evaluation by qualified scientists.

### **Scientific information in the age of "communication"**

However, it is even more important to follow attentively the far-reaching changes in progress in the world of information. Today, we are in the age of universal *communication* , in which the traditional period required for the transmission of information is shrinking fast, and in which, to quote a well-known journalist, "the media live in the immediate present" (28) , establishing the supremacy of the image over the concept, and of the spectacular show over reasoned argument. This highlights to a maximum extent the contrast between the time required for reflection and the instantaneous nature of communication. The era of communication also marks the triumph of concentration and publicity. Under these conditions, news tends to become a commodity like other commodities, subject to the same laws of the market and the same criteria of profit.

These changes seriously affect the transmission of scientific information. In the first place, they accentuate, sometimes to a very great extent, the distortions and deteriorations pointed out above. As the fight to obtain the largest numbers of viewers, listeners or readers then becomes an imperative need, the search for a scoop and for sensational or emotional material often takes precedence over any other consideration.

Certain scientific journalists are among the first to deplore, for instance, that without their agreement and often unknown to them, their articles are often given headlines that distort the article's content in order to produce an emotional impact. The National Consultative Ethics Committee has itself been a victim of this irresponsible practice. Thus, in December 1993, a public television channel reported the Committee's opinion on the prescription of antiandrogenic drugs when prisoners condemned for sexual offences were released, and the channel felt entitled to announce that the Committee had just stated that it was in favour of "chemical castration of prisoners" , thus running the risk of arousing against the Committee the indignation of a public opinion that had been seriously misled (29) .

As the number of cases in which scientific information is distorted and sometimes denatured is increasing, these powerful trends, especially on television, are affecting the financing and programmes of research. The success of the Téléthon in France and the progress made in acquiring knowledge of the human genome, to which the Téléthon contributes, cannot suppress the view that it mobilizes public generosity by the value it attaches to criteria

which are specific to the media but questionable from the scientific, medical and even moral point of view. This has created a serious problem as regards the financing of research, and its solution can no longer be shelved. The techniques of communication and promotion affect the choice of the priorities more than is desirable, by bringing into play sums which are often considerable. Is it right, for instance, that concern about promotion or the size of an audience should affect the requirements of strictly scientific, public health and ethical considerations, in determining which lines of research are interesting, important and feasible? And is it unreasonable to wish that the media-sponsored campaigns appealing to public generosity and solidarity could find other means of supporting biomedical research than the trumpeting of misleading slogans like "a cure for cancer in ten years' time", or "analysis of the human genome will mean a cure for all diseases"?

Because the powers of assessment with which a number of information organs have endowed themselves tend to be discretionary, the question of their own possible "scientific misconduct" acquires additional importance. For instance, it is becoming increasingly common for treatments whose evaluation is in progress, or even gives negative results, to be the object of reckless praise in promotional campaigns, thus arousing great hopes among patients and perhaps even unfounded criticism from medical practitioners. Yet such undue praise is seldom followed by any correction which, if it does appear, is published late, is incomplete and is given little prominence. A peculiar type of journalistic logic is even developing which involves the deliberate obliteration of any difference between certain forms of entertainment and objective knowledge. In such cases, information turns into counter-information.

An example of such devious ways, already over 15 years old, is the work published by D. Rorvik entitled "The Cloning of Man". It was presented as a feature describing a staggering but real technical achievement, which of course was purely fictitious (30). This is the approach deliberately chosen by a journal which on the first page of each issue reports as genuine scientific facts, supported by photos, freaks like a two-headed woman with a two-headed child, or a seventy-year-old woman giving birth to five fine babies. The journal is modelled on the American *Weekly World News*, and its management unashamedly defends it as a step towards "a dustbin daily...that can be read at two levels" (31) - as satirical entertainment for the "trendy" reader, and stupefying information for the naive. This is a case of radical distortion of the activity of informing, and therefore also constitutes a no less radical problem of ethics.

Another aspect of the changes now in progress certainly seems to confirm the emergence of a real crisis in the system of scientific information. It concerns the enormous weight carried by the interests connected with the development of biomedical research and its applications, which is such that any information on the subject tends more and more often to be conveyed as publicity. Scientific journalists have themselves admitted to being subject to considerable pressure in this direction, in particular from very big companies, in the form, for instance, of free invitations to go on tempting cruises or attend glamorous cultural events. Moreover, in a specific pharmaceutical research field, there is a growing number of advertisements in the form of communiqués designed to expand the self-medication market and persuade social security systems to sponsor certain products. In the last instance, one may wonder whether the advertisement does not constitute the future form of biomedical information, in an era marked by the supremacy of scientific-industrial-media complexes which are increasingly and exclusively governed by the laws of the market. Journalists, moreover, are not the only targets of such pressure, which is also exerted on scientists in many ways, for instance at biomedical research conferences.

The situation in France is all more worrying as medical weeklies of a high standard are a species which is becoming extinct. Prescribing physicians mainly receive oral information from visiting sales representatives of pharmaceutical companies, or when attending seminars whose discussions are oriented by those who finance them. As regards written information, this is now largely in the hands of dailies or weeklies which are attached to large press groups, and whose main function is to support these groups by acting as



advertising media. Most of these publications are free, have no committee of readers, and reduce medical information to brief summaries drafted by stringers who often work occasionally and are subject to enormous pressure from pharmaceuticals manufacturers. Despite some brave counter-efforts, the situation in this key field of biomedical information is therefore very disheartening.

Now, the same kind of pressure is beginning to produce disquieting effects on one of the last bastions of genuinely scientific information : the high-standard non-specialized scientific journals such as *Nature* , *Science* , or the *New England Journal of Medicine* . This type of publication enjoys undisputed prestige in the scientific community and is still considered as the ultimate reference. Today, it has become the chief source of written information reproduced by the media for the general public. However, a few events during the last few years give reason to fear a deviation in the editorial policy of these journals themselves, which might result in their having recourse to the same procedures as the press transmitting general news, such as the targeted distribution of summaries a few days before an issue's publication, and in their submission to the same commercial considerations of competition, rapidity, sensitivity to public opinion, etc. Examples of this are the curious editorial policy adopted by *Nature* in the affair concerning the " memory of water" , or that of *Science* in publishing controversial results concerning a new mode of cell penetration by HIV.

Any slackening of the rigorous accuracy with which biological and medical information should be conveyed can cause serious damage, not only to scientific exactitude, but also to public health. This was shown once again by the reluctance of the companies concerned to divulge the results of the Concord Trial, according to which immediate treatment by AZT during the asymptomatic phase of HIV infection is no better than deferred treatment. As anyone can understand, information about the limits of the effectiveness of one of the only means of therapeutic action against this infection presently available could appear contrary to the wish not to create panic among the public and even more to keep thousands of patients from despairing. An obviously estimable wish among doctors in relation to their patients, and among political leaders in relation to society as a whole, but doubtless less disinterested on the part of the companies manufacturing AZT. However, withholding reliable information is never a good solution to such problems. On the contrary, it involves the risk, in the end, of acting as a boomerang and giving rise to the very panic it seeks to avoid, and what is more, of permanently destroying the confidence of patients in their physicians.

In the words of high official responsible for research on AIDS, all these different factors in the emerging crisis in biomedical information constitute " a major problem of civilization". (32)

### **III. Thoughts and proposals**

A frequent initial reaction to the facts and tendencies described here is a feeling of fatality and therefore of powerlessness. But the present report reflects, and would like to impart, the opposite conviction. Granted that the facts in question are becoming increasingly common and the trends they reveal are enormously powerful, but inasfar as they point to disquieting or even unacceptable situations, the ethical tendency not to be resigned to them is not necessarily the weaker, as increasing evidence to this effect shows. Quite a number of researchers are worried by these deviations, and so are certain journalists. There is nothing to prevent the general public from lending them support. The stakes are too high for nothing to be undertaken.

The first essential step seems to us *to transmit* full information about the current degradation of scientific information in the biomedical field. The facts must be brought to light and the links between them revealed regardless of their apparent distortion, and their objective sources tracked down. In short, efforts should be directed towards making the

emerging crisis described above visible and credible. At the same time, care should be taken not to give way to the tendency to stop at the subjective level of reciprocal grievances between scientists, journalists and the public, however justified they may seem in particular cases. It is not that any "social constraint" can exempt anyone from ethical requirements, and an appeal to a personal sense of responsibility is by no means irrelevant, on the contrary; but in view of the problems at issue and the widespread structural nature of the crisis, the sole aim of inculcating this sense cannot be to reduce the number of individual failings. What seems to us to be at stake is nothing less than the moral credibility of both scientific research and informative journalism, and the democratic ability of society as a whole to achieve true transparency between science and itself. Such stakes demand an attitude that rises above the listing of grievances to achieve a true grasp of the problems at issue.

Within the framework of these efforts, the general *concern for ethics* is gathering strength. The alarm has been sounded by a growing number of biologists and physicians and by editorial boards of scientific publications and organs of general news. Newspapers and periodicals are devoting articles and even series of investigations to this question. Groups of scientific journalists and patients' associations are thinking about the devious practices that should be forbidden, and are even initiating steps to clear the way for new measures. Within the framework of the activities of the European Medical Research Council, which comprises the directors of European national institutes for medical research, an important statement has just been approved, analysing misconduct in medical research and suggesting remedies for it. According to this statement, the "factors of misconduct and fraud" can above all be traced to the "pressure to publish", which results, in particular, from institutional pressures, personal ambition and the lure of profit. The statement lists a series of measures which would reduce pressure to publish, including the financial pressures exerted to that end. (33) The hearings conducted by the working group responsible for preparing the present report seem to us to imply that many of the circles concerned would also welcome corresponding measures to prevent misconduct by the media as regards the transmission of biological and medical information.

We therefore believe that the necessary conditions seem to be taking shape for the *organization of reflection and even proposals* concerning, for instance, the following :

- deontological rules for the disclosure of information by researchers and research institutes;
- deontological rules or even a charter for scientific journalism;
- rules of "good conduct" for researchers when dealing with the media, and conversely;
- measures designed to help researchers and journalists to resist the financial pressures to which they may be subjected, and
- concerted measures aimed at training the general public to form critical judgments in these respects;
- all this should be done through interdisciplinary seminars promoting the exchange of viewpoints, suggestions and experience in different fields. A decisive role in launching such a process can be played by organizations like the governing bodies and scientific committees of research institutes, editorial boards of newspapers and periodicals, managements of radio and television channels, and the associations representing the professions concerned.

Within this emerging framework there is one precise urgent problem which we believe should be tackled with a firm desire to find a solution : it is that of *correcting false information* harmful to one of the agents involved in news transmission and even to society as a whole. As has been shown in many cases, scientific information that can be contested on precise points is today seldom the object of indispensable corrections, despite the

cultural and sometimes social harm it can cause, and the rare corrections are virtually never given the same publicity as the general announcement (34) . To admit publicly to having made a mistake, let alone to having been misleading, is not a usual practice, even among researchers(35).

This ethically unjustifiable state of affairs gives grounds for the most serious concern. Of particular relevance here is the increasingly frequent question of defining the ethics of journalism and also the ethics now taking shape concerning the disclosure of information by researchers and scientific institutes. When considering the problem of how to control the "skidding" of information, Paul Valadier, acutely conscious of the difficulties involved, envisaged possible solutions, including an audiovisual council of officials and professional representatives on the French model, or an ombudsman. " But should they" , he asked, " represent the entire press, or a particular newspaper ? This constitutes a real problem. It is necessary for professional and ethical reasons to tackle this problem, otherwise there is the risk that the legislator or the political authorities will impose measures that would not be very auspicious. At least one question must be raised : *how can regulation (of news transmission) be achieved ?*" (36).

One proposal inspired by the discussions within our working group seems to us to deserve consideration : the constitution of an *interprofessional consultative committee* capable of promoting an exchange of viewpoints and a common search for solutions to the serious problems raised in this report.

The committee could be interprofessional by common consent of the representative bodies of scientific research and of the media, and be composed of leading figures whose intellectual and moral authority would be uncontested both in their own fields and those of their partners. Being consultative, its sole powers would be those conferred by the wisdom of its opinions. One of its functions would be to pursue the reflection started in the present report. As a forum for the concerted agreement on and definition of ethics governing scientific information, it could stimulate both reflection and the drafting of measures concerning unethical behaviour. When informed of legal disputes concerning the harmfully erroneous character of biological and medical information, it could be authorized to recommend that the authors responsible correct such information if it deems this justified. In case of refusal without what it considers sufficient motive, the committee would be entitled to make public its recommendation and the reasons for it.

Whatever one's appreciation of such a proposal, we believe it extremely desirable for the competent professional bodies and associations to take note of the problem at issue in order to solve it. We are perfectly aware of the difficulties of various kinds which will have to be overcome, but we do not consider them insoluble, once the very different circles concerned become determined to put a stop to the disquieting degradation of scientific information which is evident in the biomedical field.

By putting forward these considerations and proposals, and more generally by making public the justifications underlying them, the French National Consultative Ethics Committee is convinced that it is faithfully carrying out the task entrusted to it : that of publicly tackling the great moral problems concerning research in the fields of biology, medicine and health, especially when they affect society as a whole.

## Addenda to the report

### ON THE TRANSMISSION OF SCIENTIFIC INFORMATION RELATING TO BIOLOGICAL AND MEDICAL RESEARCH

Some worrying facts affecting the ethics of scientific information in biology and medicine are becoming increasingly frequent. Because the French National Consultative Ethics Committee was concerned at this state of affairs and the trends it appears to reveal, it resolved to deal

with the problem itself, and to undertake an investigation whose provisional results were contained in a report submitted to public debate in December 1994, during the days annually devoted to ethics. The very varied reactions which the report has aroused, both then and since that time, led the Committee to extend its reflection by defining its attitude on controversial points and adding new ideas and information to the original report. These additions are the subject of the present complementary document.

The way in which scientists and journalists treat texts dealing with scientific information is already in itself instructive as regards their attitude to the report. The interest in and support for this report shown by researchers and journalists in France and other countries seems to show that the concern it expresses is shared, although in varying degrees, by more than a few of the protagonists in the domain of scientific information in general, and of biological and medical information in particular. The clearest sign of this in our opinion is the organization in March 1995 by the Newspaper and Periodicals Scientific Journalists' Association of a meeting on the subject of Researchers/Journalists : Who manipulates Whom ?

During this meeting, which was followed with great interest, many facts illustrating the frequency of real deviations (1) were quoted, and these illustrations help to understand why the deviations occur. One of the most striking -which was not mentioned in our report- concerns the number of professional scientific journalists. Out of about twenty-eight thousand journalists in France today, only a little more than two hundred are scientific journalists (2) . Consequently, many daily newspapers, especially in the provinces, are not in a position to report developments in research themselves, and leading television channels have no science department. And it is hard for the few scientific journalists to cope with the fast-evolving complexity of highly specialized disciplines. This flagrant disproportion no doubt does much to account for the deficiencies and some of the deviations we have stressed. At the same time, the participants in the Scientific Journalists' meeting referred to above raised, for very different reasons, several important problems which we shall discuss below.

We naturally welcome favourable responses to our reflection and its motivated confirmation, but we pay just as much attention to the absence of response and to the objections formulated. The complete silence regarding our report in the written press and audiovisual media has not gone unnoticed, the more so as CCNE documents are usually always presented and commented on. It is tempting to interpret the silence as a confirmation of our remarks concerning the criteria governing the choice of news items to be transmitted or not transmitted, an especially hard test for the ethics of journalism. As regards the critical reactions of professional researchers and media members, these, as far as they are known to us, concern chiefly three main questions which it is important to examine thoroughly.

## **In what sense is there an "emerging crisis" in biological and medical information ?**

The reference to an emerging crisis is the main idea developed in the report. It was not understood by certain researchers and journalists. Although nobody denies that many examples of bad practices can be found to illustrate it, or even of scientific fraud or manipulation of the media, those who do not believe in the crisis maintain that such cases are not *proportionally* more numerous than before, considering the mass increase in the volume of scientific information produced and transmitted. And according to a very widely held view, the causes of reprehensible conduct, now as in the past, are perennial failings of the human character : the thirst for celebrity, ambition for a career, the lure of gain, ideological partiality, incompetence, and irresponsibility or even mental disturbance.

This idea of the " constant proportionality" of failings in relation to the overall volume of scientific information produced and transmitted deserves to be examined. To all intents and

purposes, all that its supporters have in mind are cases of patent fraud, which are still doubtless marginal. They do not seem to take into account the very varied forms of scientific misconduct connected with distorted transmission via the media, which constitute the essential part of the problem. In addition, it is important to stress, as did the authors of a recent article (3) , that the mass increase in the number of people professionally employed in research, and the growing interest of the public in scientific activities make the various forms of misconduct much more typical and qualitatively different. From the purely mathematical viewpoint of proportionality, the ratio of a hundred to ten thousand is obviously the same as that of one to a hundred. Nevertheless a single case of misconduct is an individual exception, whereas a hundred cases already constitute a social fact.

Thus, what is masked by the " constant proportionality" argument regarding the cases of scientific misinformation - an argument which, moreover, we do not believe conforms to observable reality - are the qualitative differences that we have undertaken to analyse. And one of the most important differences is precisely that today, dishonest practices no longer only involve individuals, but communities - including scientific communities in their relations with the media.

For one needs to measure the structural transformations which have taken place during the last few decades in the field of scientific information - especially as regards biological and medical research. In a reference to the 1969 meeting that the Scientific Journalists' Association organized on this general subject in Nice, Robert Clarke recalled that at that time, the major fact was " the absence, in the world of science, of a real will to inform the public, and the very great fear of researchers that they would not be understood and that their statements would be distorted and " sensationalized" (4) . Since then, the opposite situation has been created : not only are many researchers very far from fleeing the media, but public relations departments have been springing up more or less everywhere, as well as communications managements attached to research institutes and laboratories. As the purpose of these bodies is to facilitate relations between researchers and the public by means of the media, they naturally, and very professionally, tend to promote behaviour whose logic is that of communications techniques. And the final aim of these techniques is to convince the public of the value of " products" competing on the market, which is quite different from assessing the evolution of a piece of research and the significance of a discovery.

Consequently, far from thwarting the tendencies of individual researchers to seek celebrity favouring personal promotion or the obtaining of an allocation of funds, the general application of the techniques of communication to the transmission of scientific news involves a risk of oversimplification and slanted presentation. Such attitudes are supposedly justified by the overall interests of an institution. This is indeed a qualitatively new problem - the problem of communications policy - which transcends the behaviour of individuals and concerns the attitude of the directors of laboratories and research institutes. It seems to us essential to consider this point when searching for a remedy for unfortunate practices. Although of course an appeal to personal ethics is always appropriate, it does not do away with the need to consider communal initiatives and institutional measures capable of counteracting tendencies of a social character.

The same can be said of other attitudes which have spread among the scientific community during the last decades - for instance, the often intense and sometimes " appalling" (5) institutional pressure exerted on researchers to publish. We believe few scientists in France question the reality and harmful nature of this pressure, and the need to reconsider it. Similarly, the observation that " the role of money is making itself increasingly felt" (6) has been confirmed by very many journalists and researchers. And it does not seem very reasonable to attribute the extremely harmful effects of this openly increasing role solely to the action of immutable psychological factors, even though they do undeniably exist.

After taking due note of the present diversity of the reactions to the diagnosis of an " emerging crisis" in scientific information relating to biology and medicine, we nevertheless do not think that the existence of new social trends with perverse effects can be denied, and

neither can the need to deal with them without delay in a collective and pluralist fashion. Moreover, the present development of studies, publications and even authoritative recommendations concerning scientific misconduct confirms, in our view, that this is an ethical task in which the public interest is deeply involved.

## **Are there specific ethics of scientific information ?**

The wish to remedy the various forms of malfunction observable in the transmission of scientific information has led to some debate on the specific or non-specific nature of the ethics governing this activity. However, this way of presenting the problem seems to us inappropriate, because it confuses ethics and deontology. The listing of the duties pertaining to the exercise of a particular profession constitutes what is known as deontology. Ethics, however, no matter how one defines them - and goodness knows in how many senses the word can be understood - go far beyond any such particularity, because the stakes they involve are universal, inasmuch as ethics are concerned with man himself in each particular situation. Deontology brings the individual face to face with the rules of his profession, whereas ethics concern the demands of conscience. Clearly, therefore, there cannot be *specific ethics* for scientific information, any more than for any other particular activity. And moreover, this is why the term "bioethics" is so contestable. For it can give the impression that for such ethics, biomedicine is the source of inspiration, whereas it is only the field of intervention.

What is specific about the transmission of scientific information does not concern its ethics but the kind of situation these ethics have to cope with and the resulting types of responsibility. These situations and responsibilities are dominated by the striking discrepancy at every stage of transmission between the *scientific character* of the information to be conveyed and the *scientific inexperience* of those destined to receive it, and even sometimes of those involved in its transmission. One can of course object that the transmission of any type of information implies that those in possession of the information are better informed than those who are not. But in the case of scientific knowledge, the special difficulty lies in the fact that the inequality concerns not only the possession of information but the ability to understand and even to receive it. Real as opposed to formal transmission of scientific information means making it intelligible to the recipient. In that sense, the term *transmission* is a weak definition of a set of actions that in certain respects resemble the complex tasks involved in translation, which, as is well known, can easily misrepresent the original.

This is first of all true as regards the researchers who produce new knowledge and the journalists whose function is to make it known. At the source of any item of scientific information there is always a written or oral explanation of the result of a piece of research by its author or authors. However, in its original form, this explanation is designed for specialists, the only people fully able to understand and evaluate it. To make it more widely accessible, the report must be stripped, if only in part, of its esoteric character. And it is here that the great responsibility of the scientists intervenes in the question at issue - a responsibility that must be borne by the research institute when communication policy comes into play. The inequality of competence gives the researcher power over the informer, and ethics forbids any abuse of this power. This is doubtless the newest aspect of the traditional problem of scientific information. It means that the elimination of unethical practices is a task for which not only journalists but also scientists themselves are responsible.

This is also true of the journalists and the press organs for which they work, as the same kind of inequality applies to the scientific journalist, who is often the only editor able to understand and correctly evaluate the nature and scope of a discovery. He therefore has to assume specific responsibilities, both in relation to the researchers and to his publication. These responsibilities can be defined as competence, honesty and critical vigilance. The directors and editorial boards of the written and audiovisual media also have their own

reciprocal responsibilities, such as not covering the evolution of research without being in possession of qualified means to do so, or not distorting on their own initiative a correct piece of scientific information by deceptive headlines or forms of presentation.

Lastly, this inequality is true of the relations between the media and their respective publics, because one cannot transmit valid information on the progress of research to a public opinion without the slightest scientific culture. This is why the problem of transmitting scientific information is closely bound up with that of instructing the public in scientific matters. But apart from the professional staff working for educational organs, it is common knowledge that professional journalists working for the media generally consider that their function is not to teach. Here there is doubtless a misunderstanding which should be cleared up. It goes without saying that although scientific journalism includes the task of supplying the public with concise explanations regarding facts, terms or ideas, it cannot be considered to include the *function* of teaching. Much more modestly, its specific and important responsibility seems to us to be accurate assessment of at least the pedagogical *effects* that a particular piece of scientific news can be expected to have in view of the way in which it is transmitted. In the field of biology and medicine, one can, for instance, expect the media to refrain from arousing groundless anxiety about known treatments, or illusory hopes about the time required to perfect a new treatment. It is also just as wrong to appeal to the prejudices of the general public and not to its judgement, by claiming, for example, that there is a demand for news about the pseudosciences, without envisaging a possible demand for a critical attitude towards them.

In none of the relationships just mentioned is there any need for specific ethics : in these as in other respects, the need is to inform persons and never to treat them as mere means, but always also as ends. What is specific to these relationships is the kind of power conferred by scientific knowledge over those who do not have it, and therefore the kind of fearful abuse of power that this inequality makes possible. When, as we consider is the case today, such abuses of power not only satisfy compulsive individual ambitions but social trends of an institutional, economic and financial order, the deviations become more numerous and more serious. Our report is designed as a warning against this situation.

## **What are the alternatives to a disquieting "control" of scientific information ?**

In the category of desirable initiatives, the reactions to our report strongly highlighted the sometimes obsessive fear among journalists as a whole and even researchers of a possible outside *control* of scientific information. This fear is so strong that some people thought it was foreshadowed by the comments of the CCNE, although anyone who has read our report can understand that such an idea is absolutely foreign to both its spirit and letter. The proposals made in the last section of the report, including the one concerning a consultative multidisciplinary committee, are all expressly based on responsible and as far as possible joint initiatives, to be implemented by journalists and researchers and by them alone. If anything were liable to give rise to a risk of some kind of control of scientific information, it would, in our view, be that the communities concerned prove incapable of stemming the malpractices observable by all.

Like all the professions involved in the media, we too refuse to countenance any infringement of freedom of the press and the independence of journalists, and we therefore do not reason in terms of control. However, if the alternative proposed to the disquieting possibility of outside control were individual control that merely relied on each person's sense of responsibility, this would surely be a sign of failure to grasp the unprecedented dimensions that the problem has today acquired. We believe that a real capacity to contest institutional policies, social trends and economic pressures which generate misconduct in the realm of scientific information requires concern for ethics to become not only personal, but collective.

Here, however, this concern comes up against an undeniable epistemological difficulty : there have been claims that the desire to judge whether a piece of biological or medical information is " scientifically correct" means being caught up in the sinister process that would lead in theory, to the recognition of an infallible superscience, and in practice, to the institution of an official scientific truth. The very formulation of such ideas is enough to reveal their profoundly unacceptable character. In that sense, the issue is not only the idea of de facto control but the very norm which is the basis of a principle. This marks the extreme limit of any conceivable deontology concerning scientific information. Once it has been recognized that truth only makes sense in the evolutionary, relative and contradictory process of verification, it becomes clear that any tracking down of scientific misinformation presupposes, above all, the transparency of the reasons for it, pluralist points of view, and a constant open-minded attitude to critical exchanges, which in themselves imply that access to the media must be equal for all. Exclusive rights and privileges concerning this access are therefore extremely harmful to the intellectual and moral standards of scientific information.

It is none the less true that a legitimate need for accuracy does exist, and that although there is no absolute scientific truth, there are errors which have been established beyond a doubt. In this limited but important domain, we would find it unjustified to make the extreme evolutionary complexity of science a reason to shirk the elementary demands of reliability. It does, for instance, seem surprising that scientific journalists do not consider it necessary to submit to a researcher, before publication, the statements made during an interview which they intend to quote as his words. It is even more shocking that the correction of items of information which are easily refutable and sometimes definitely damaging, is still so often late, inconspicuous and in certain cases impossible. The codification of the right to reply when personal integrity is doubted has in no way detracted from freedom of the press, any more than we consider there is any law against envisaging the right to a correction when indisputably erroneous biomedical information is published.

We do not deny that although our approach has met with many favourable reactions, certain scientists seem unconvinced, despite the dangers of our present situation, and many journalists who are obsessed with the risk of control seem to disapprove of any kind of responsibility other than individual. We therefore attach great importance to any signs of a new sense of awareness and responsibility, ranging from the present attempts to update and complete the Journalists' Charter drafted in France in 1918, to the efforts made by the scientific community to draw up codes of good conduct for researchers (7) .

However, we believe that much more will be needed for a real reversal of present trends. There will have to be common determination on the part of the two communities directly concerned to organize exchanges of experience, points of view and proposals, and to tackle energetically important complex questions like the system that obliges researchers to keep on publishing without pause or reprieve, institutional policies of communication, the unhealthy complicity between certain researchers and journalists, the responsibility of audiovisual media managements and of editorial boards of the written press, the correction of erroneous information, the ethical aspects of professional training for research and for communication via the media, the forms and means of resisting both private and public economic and financial pressures, and other questions besides.

As we felt entitled to write in our report, organisms like the management and scientific committees of research institutes, the editorial boards of press organs and the directors of radio stations and television channels can, in our opinion, play a decisive part in initiating such cooperation. This cooperation, of which what we described as a consultative multidisciplinary committee is but one possible expression, stands to gain much from the resolute support of the citizens in appropriate forms and at suitable times, because in the last resort the whole of democratic society is concerned by its relations with the evolution of science.

As the scale of the problem is international, it is certainly instructive to look attentively at developments outside France during the past few years. In countries like Sweden, where



there has been an ombudsman ever since the sixties, Britain, which has had a Press Complaints Commission since 1991, and Quebec, with its recently set up Council of the Press, organisms now exist which have no judicial powers but real moral authority, and disputes can be referred to them concerning information, including scientific information. In Germany, the Press Council (Deutscher Pressrat) an autonomous non-governmental organism set up in 1956, has elaborated a Press Code, in which Principle n°14, dating from 1992, deals expressly with medical information. Directive 14.1 states the following : " It is advisable to avoid, in the text and presentation, anything which is liable to raise unfounded hopes of a cure among patients and the members of their families, and does not correspond to the present state of medical research. In addition, the press does not have the right to raise doubts among patients and make them unsure of the possible success of treatments, by publishing critical or even partial reports of extremely controversial opinions." (8)

In mentioning these facts we in no way intend to set them up as models, for each country has its own traditions and conditions. But in the first place we consider them as proof that the concern expressed in our report is shared, both in Europe and outside it. Secondly, as far as we know, the press in Sweden, Britain, Quebec and Germany is not usually considered less free than in France, which seems to us to indicate that it is perfectly conceivable to take autonomous, institutional, ethically-orientated measures with a view to finding better solutions to, among others, the problems dealt with here. This is surely the kind of way in which to seek original solutions adapted to the traditions and conditions that prevail in France.

This additional text was enriched, especially in the last part, by the valuable contributions of Mrs. Anne Bernard.

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## Notes

1. See " Tintin au pays des éprouvettes" (Tintin in the land of test tubes), *CFJ-Info* Supplement, n°20 1, May 1995. The following is one of many examples found since the publication of our report : The weekly *Le Point* gave front-page coverage, in its issue of January 7, 1995, to what it called a " medical revelation" , i.e. " the fantastic discovery by Professor Baulieu" (it concerned the DHEA molecule which seems to possess biological properties which are extremely active against certain ageing processes). In fact, however, this molecule was discovered thirty-five years ago ! In an interview with Chantal Guéniot published by *Le Point* , Emile Baulieu, while stressing that " he was not at all pleased" with the coverage envisaged for the issue, stated : " We need money, and if this publicity in the media can induce scientists to run trials, I shall be very pleased."

2. Note, in comparison, that there are about two thousand sports journalists in France.

3. See D. Alberts and K. Shine : Scientists and the integrity of research, *Science*, vol. 266, December 9 1994, p. 1660-61. The authors are respectively the President of the National Academy of Sciences of the United States of America, and President of this Academy's Institute of Medicine.

4. Robert Clarke, The Nice Conference, records of the March 1995 conference organized by the French Scientific Journalists' Association.

5. The term used by Philippe Kourilsky in an article entitled " drifting" , *Le Nouvel Observateur*, May 12-18 1994, p. 22.

6. Ibid., footnote 27.

7. See, among other articles " L'éthique du journalisme" , *Médiapouvoirs*, n°13, January-

March 1989, and among many books, " *Journalisme et Vérité* " , by Daniel Cornu, Ed. Labor et Fides ; *Diffusion et Vulgarisation - Itinéraires du texte scientifique*, Annales Littéraires de l'Université de Besançon, Les Belles Lettres ; *Ecrire la science*, by Yves Jeanneret, Ed. PUF. See also David Evered and Philippe Lazar, " Misconduct in medical research" , *The Lancet*, vol. 345, May 6 1995.

8. Sources : *Press Law Practice - A comparative study of press freedom in European and other democracies*, UNESCO, 1993.

9. It may seem surprising that the examples in the present report are more often taken from the press than from radio or television. This unintentional imbalance is due to the fact that critical analysis of the press can easily be substantiated by written material in press files, whereas the corresponding documentation relating to information on radio and television is much harder to obtain. The problems seem to us to be similar for the written and audiovisual media, and are even often amplified in the latter.

10. See the survey of this subject by Jean-Marc Lévy-Leblond " Un savoir sans mémoire" (Knowledge without a memory). *Le Genre humain*, n°18, Automne 1988, p.199.

11. Certain specialized journalists keep an " address book" that enables them to obtain quickly the opinion of research scientists who are authorities in a particular field and can guide them in their appreciation of current scientific events. This method has its advantages, on condition that the indications supplied by the scientists consulted are absolutely correct, not only scientifically, but ethically.

12. We quote from the remarks of Jean Daniel, editor of the French weekly *Le Nouvel Observateur*, in his testimony before the working group responsible for drawing up this report, given on October 21 1993.

13. This statement was cited by Axel Kahn at the seminar entitled " Patrimoine génétique et Droits de l'humanité" (Genetic Inheritance and Human Rights) whose proceedings were published under the title *Vers un anti-destin ( towards an anti-destiny)*, Ed. Odile Jacob, 1992. The sentence quoted is on page 519.

14. On this point, see the article by Elisabeth Dufourcq entitled " Signification scientifique et décision politique" (Scientific Significance and Political Decisions) in *Le Monde*, May 6, 1993.

15. See Sylvestre Huet and Jean-Paul Jouary, *Sciences : les Français sont-ils nuls ?* (Are the French hopeless ?), Ed. Jonas, 1989.

16. David Filkin, Director of the BBC's scientific programmes, said in a statement justifying British efforts in this field : " We need a population with a good knowledge of science to regulate the future by taking part in decisions." ( *Le Monde-Radio Télévision*, weekly issue for October 17 to 23 1994, p. 34).

17. On this point, see Stephen Jay Gould, " *La malmesure de l'homme*" (Mismeasurement of man), Ed. Ramsay, 1983.

18. To ascertain how far one can legitimately conclude from a significant statistical correlation between an X and a Y factor that there is a causal link between them is an extremely complex undertaking. Its incorrect treatment has given rise to countless errors and cases of confusion, not only among those who transmit and receive scientific information but sometimes also among those who produce it. This calls for a few explanations :

19. This work was done by the Professor Dean Hamer and his team. Note that the APM report from Washington dated July 12, from which these articles in the press originated, expressly indicated that the researchers concerned had stressed that no gene was identified during their work that they did not claim that genetics alone could explain human sexuality.

However, several French newspapers and periodicals ran headlines and sub-titles to their articles on the subject featuring " the isolation of a homosexuality gene" ( *Le Monde*, July 17-18, 1993) or even a " gene of the third sex" ( *L'Express*, July 22), going as far as to indicate that " according to a team of the very reliable American NIH, a fair number of cases of masculine homosexuality might be determined by the sexual X chromosome" (Le Quotidien de Paris, July 16). Other newspapers, including *Libération*, July 17-18 and *L'Humanité*, July 19 ran headlines expressing doubt as to the news by using question marks or the term " hypothesis" .

20. The article referred to was published in the *New England Journal of Medicine* and was entitled " Gene Cloning by Press Conference" , March 27 1980, p. 743.

21. An example of this, among many others, seems to be what has just happened about the so-called " breast cancer gene" . For several years, breast cancer has been known to be familial. On September 14, 1994, a television broadcast, followed, the next day, by an article in the *New York Times*, made sensational announcements about the discovery of the gene responsible by a Salt Lake City research team. The media all over the world repeated the story. It was only on October 7 that the scientific study in question appeared in *Science*. The BRCA 1 gene does seem to be a gene for sensibility to breast cancer but it is only found in half the forms of familial cancer. Given its length, the authors do not think they can elaborate a simple diagnostic test. Moreover, it is not at present known what preventive strategy should be adopted. Bilateral mastectomy is sometimes suggested. Fifteen of the 45 authors of this article belong to academic institutions and 30, to biotechnology companies, mostly Myriad Genetics, also located at Salt Lake City, where the senior academic author, M.H. Skolnick, works too. Naturally, applications for patents have already been made. Agency despatches have not reported how the shares of the firms concerned have been doing on the Stock Exchange since September 14, 1994...

22. This is the case for the American biologist David Baltimore, winner of a Nobel Prize for Medicine, and author of an article published in a well-known scientific journal which turned out to " contain results that were entirely fabricated" . When acknowledging the fraud, he stated in defence of the colleague who assisted him that " if the results were made to measure, it was the fault of the NIH, which exerts intolerable pressure on its researchers, who are forced to publish constantly to obtain subsidies." ( *Libération*, March 28, 1991). See, on this subject, the study of the Baltimore affair, published in *La Recherche*, n°240, February 1992.

23. See J. Swazey in *American Scientist*, November 12 1993.

24. CCNE, Opinions from 1983 to 1993, p.316.

25. See Dominique Foray " L'économique aux commandes" (Steering by economics) in " Science, power and money" , Ed. Autrement, Sciences en Société series, n°7, January 1993, p. 58-66.

26. In the contaminated blood affair in France, the role of political leaders and scientists (i.e. the functioning of institutions and the responsibility and guilt of individuals) has been and is still being widely debated and evaluated by the public and in the courts simultaneously. The same does not apply to the role of the media, even though it was determinant, in particular in revealing the faulty functioning that gave rise to decisions with disastrous consequences. The way in which the different press organs fulfilled their respective tasks is only now beginning to be the subject of critical studies like the one by P. Champagne and D. Marchetti entitled " L'information médicale sous contrainte" (Medical information under constraint), in *Actes de la Recherche en Sciences Sociales*, n°101-102, March 1994. Moreover, this article was disputed by a group of journalists in a " Lettre ouverte à Pierre Bourdieu" (Open Letter to Pierre Bourdieu) in *Le Généraliste*, July 13 1994. The work done by the media therefore remains to be evaluated, not only as regards the revelation of the facts at issue, but also in the way they were related and evaluated. Their treatment can serve as an example for the study of public awareness of the social interests connected with

the fast evolution of knowledge, and the study of the difficult relations between the powers of the political authorities, scientists and media.

27. On this point see, for instance, " Le scandale américain des tests radioactifs" (The American scandal of radioactive tests), in *Le Figaro*, December 22nd 1993, and more generally, the daily press of the last days of December 1993.

28. The phrase was coined by Jean Daniel in the testimony cited in footnote 3.

29. See the CCNE opinion dated December 7 1993, in *Opinions issued by the CCNE since its 10th anniversary* (February 8-9 1993).

30. D. Rorvik, *In his Image, The Cloning of Man*, Publ. Lippincott Co., Philadelphia. See J. Gooldfield, *Reflections on Science and the Media*, AAAS, Washington 1981.

31. The journal in question is *World News*. The sentence quoted is from Stéphane de Rosnay.

32. Professor Jean-Paul Lévy, Director of the French National Agency for Research on AIDS.

33. Report published in *The Lancet*, 345, pp 1161-1162, 1995.

34. " After the committee responsible for regulating the publicity given to, and the diffusion of, recommendations on the proper use of medical drugs has given its opinion, the Medical Drugs Agency can ask for an advertisement to be modified, ban it or demand the diffusion of a rectification. The latter possibility is virtually never used" , wrote Laurence Folléa when commenting on the elaboration in France of a draft decree on controlling advertisements for medical drugs ( *Le Monde*, August 21st-22nd 1994).

35. On this point, see Michel de Pracontal's interview with John Maddox, Director of *Nature*, published in *Le Nouvel Observateur*, May 12 to 18, 1994. Quoting the example of a very important erroneous piece of news about AIDS which *Nature* had published and had been front page news in the *New York Times*, J. Maddox noted that " We published an editorial to explain the error, but we had great difficulty in persuading the authors to write that they had been mistaken, even if the mistake was bona fide."

36. Paul Valadier, " Le journalisme entre l'éthique et la morale" (Journalism between ethics and morality), *Le Supplément*, n°190, September 1994, p. 205.