National Consultative Ethics Committee for Health and Life Sciences

Opinion n°109

Society and the communication of scientific and medical information: ethical issues

Members of the Working Group:

- Annick ALPEROVITCH
- Ali BENMAKHLOUF
- Claude BURLET
- Pascale COSSART (Rapporteur)
- Roger-Pol DROIT
- Patrick GAUDRAY (Rapporteur)
- Emmanuel JOLIVET
- Claude MATUCHANSKY
- Philippe ROUVILLOIS
- Dominique STOPPA-LYONNET

Persons heard:

- Marie-Agnès BERNARDIS, *Chargée de mission,* Cité des Sciences et de l'industrie, Paris
- Dominique LEGLU, Editorial Manager of the monthly magazine *Sciences et Avenir*
- Marie-Odile MONCHICOURT, Scientific Editor, France-Info.

OUTLINE:

RECOMMENDATIONS

Make perfectly clear to citizens that the validation of scientific information is of critical importance
Urge and encourage scientists to improve their communication skills
Encourage action to raise the level of basic scientific education.

INTRODUCTION

Professor Alain FISCHER, at the time a member of CCNE, asked the Committee to consider the ethical issues involved in communicating scientific and medical information to the media. Some of these statements may give rise to false hopes or disillusion and magnify some of society's doubts on the role of scientific research, in particular medical research. CCNE addressed this singularly sensitive issue, but extended its scope, and is proposing recommendations aiming to improve the quality of the information that scientists should pass on to society. They should help members of the public to gain a better understanding of the potential impact, individually or collectively, of advances in the biological and medical sciences.

The relations between science/medicine and society, particularly as regards scientific information and its dissemination, have in fact changed considerably over the last fifteen years and raise a number a number of new ethical issues. This change has come about, to some extent, through the complete technological revolution brought to society by generalised access to the Internet. Today, thanks to the Internet, everyone can obtain limitless scientific information, some of which is well founded (via access to recognised scientific journals or information posted on-line by undisputed institutions such as the *Collège de France*) but also information which is either insufficiently validated or not validated at all. This change stems also from the emergence or re-emergence of risks that citizens see as directly or indirectly linked to scientific breakthroughs — often because they are not aware of the facts of the case. Some examples are: the appearance of bacteria multi-resistant to antibiotics, the crossing of species barriers and appearance of the so-called 'mad-cow' disease, re-emergence of diseases that were thought to have been almost entirely eradicated (tuberculosis). Apart from these known risks, more hypothetical risks, such as those connected to the impact on human health of GMOs or of mobile telephones are the subject of numerous discussions within society. Finally, subjects which earned a great deal of media exposure, such as the contaminated blood or growth hormone court cases, encouraged the public to consider from a more general angle the risks that could be generated by some scientific discoveries.

In 2002, the *Conseil Economique et Social* pointed out that: "growing public concern over some aspects of scientific development was less directly related to science itself than to its applications"[1]. A concept in general terms, the actual progress achieved by a scientific discovery and its therapeutic impact are reasonably comprehensible for the public at large. It is therefore deontologically important to give citizens reliable information on the fundamental aspects of a discovery and to be particularly cautious in commenting on potential applications. As Alain Fischer said in his referral: "premature or rash communication of information which *in fine* may turn out to be invalid is counter-productive"[2]. Such announcements can lead to a real confidence crisis and thereby a breakdown of the dialogue between the scientific community and the public.

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1 Interim report by the Conseil Economique et Social: "Société du Savoir et Citoyenneté", December 2002.

2 Alain Fischer, letter of referral to CCNE concerning "*...communication of scientific and medical information to the media*", November 23, 2007.

Contrary to the private dialogue between doctor and patient, the interchange between the scientific community and society is not direct. In most case, those who "disseminate information", the "media", step in. They play an important role and it may well go beyond being simply a messenger. A major problem with this transmission, in particular by the 'mass media', is that that the scientific message is often conveyed without there being any precise information on who will be receiving it[3]. The diversity of cultures and expectations of those receiving the message is a reflection of the diversity of society as a whole. To be precise and comprehensible for the majority of your audience, without simplifying the message to an extreme for fear of it becoming inaccurate as a result, requires effort and skill to a degree that is often underestimated.

One of the major reasons underlying this Opinion is in fact closely connected to the concept of "informed consent", one of the fundamental ground rules of medical and scientific ethics for over sixty years. The information imparted by a doctor or a scientist must be such that those who receive it can make a free and informed decision: opt for a given treatment in preference to another, accept or refuse to participate in a research project, etc. If the information is incorrectly transmitted — if it is not complete, honest and comprehensible for a layman — 'informed consent' becomes meaningless.

In 1995[4], CCNE had already discussed issues connected to the dissemination of scientific information, mainly as regards its mediation — and therefore its transmission — and focused on proposals for deontological rules mostly aimed at the media. The main thrust was on the potential conflict between scientific breakthroughs reported by the media and the probable lapse of time between a fundamental scientific discovery and its possible applications — marketing a vaccine, for example — and the need for that lapse of time to be clearly stated and discussed. CCNE emphasised that responsible scientific information must include a note of caution on its limitations and mention the pluralist concern for the possibility of contradiction and/or criticism. The Committee deplored the excessive, and increasingly excessive, insistence on early publication by researchers, which was likely to generate unsound practices. The report highlighted an emerging crisis born of the advent of the Internet and also noted that the increasingly important role of money is a factor that can be detrimental to the honesty and independence of information.

In fifteen years, both the scientific community and the dissemination of information have changed considerably in certain respects. This Opinion, which aims to complement Opinion n° 45, seeks to underline the new ethical issues related to the communication of scientific and medical information to society and to formulate relevant recommendations.

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3 *"The act of communication is intended to seduce, convince or share. Generally those who receive the information are not in phase with you. All attempts to communicate are frustrating and lead to the discovery of non-communication (...) The process of transfer or transmission turns into a process of negotiation". Dominique Wolton, in* Conseil national de l'Ordre des Médecins Paris, les jeudi de l'Ordre, April 26, 2007.« Ethique de l'information médicale ».

4 CCNE's Opinion N°45 on Ethical questions arising from the transmission of scientific information concerning research in biology and medicine. May 31, 1995.

REPORT

I - Science, communication and society: a new situation

I-1 Society's current image of science

According to an opinion poll organised by the *Institut CS*A and circulated by the *Ministère de l'Enseignement Supérieur et de la Recherche* in 2007, 94% of French public opinion consider that science is useful to society and 85% trust science[5]. It would seem, however, that today's society is more critical of science, in particular of scientific 'certainties', than it was several decades ago at a time when a degree of scientism sometimes prevailed. The reasons for such change are numerous, some of which are mentioned above (the Internet revolution, the high degree of media exposure granted to certain medical risks, etc.). So as to prevent this critical attitude, in itself both legitimate and beneficial, from evolving into mistrust, scientific and technical research needs be transparent and the public must be kept constantly informed of progress. It could be said that science needs to be accountable to society.

One of the major reasons why the public is becoming wary of science's contribution to society stems from the confusion or the lack of discrimination between the importance of a scientific discovery and its possible applications. Generally, the public sees science through the prism of potential applications. But scientific discoveries are frequently related to fundamental concepts or mechanisms whose actual impact as applications can only rarely be anticipated: was it likely, for instance, that the laser, which was a discovery in fundamental physics, was going to be used to treat ocular disorders, as well as for several other medical applications?

The image of science and the image of scientists do not entirely coincide perceptually. Society as a whole sees scientists as experts from whom almost messianic answers to questions are sometimes expected.[6.] Scientists, by their very nature, question and question themselves perpetually. Answers, for a scientist, are more like a call for more questions and the start of new research than an end in themselves.

In the past, science has played a part in the development of convictions and values in most of the societies existing today. Scientific work was occasionally in conflict with the beliefs of the time. Scientists played a decisive role in their revision, thus contributing to the emergence of new cultural — or even anthropological — references.

No one can deny that in the course of our history, Science has been the source of progress and has contributed to improving human well being. The gradual increase in life expectancy is linked, at least partly, to progress in curative or preventive (vaccines) medicine and to behaviour (hygiene) which is a direct result of scientific discoveries. While it must be emphasised that certain philosophical and/or religious beliefs may still lead to negative attitudes or reactions to scientific advances, they are more and more in

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5 « Les Français et la science », poll by the Institut CSA – October 2007 – N° 0701190C

6 "*What is strange is that living under the overwhelming pressure of current events, increasingly cut off from the future, where prophecy fails, an obscure message is sought from divinatory genetics. Very often, the promise of an awesome future, mastery leading to loss of mastery, destabilises public opinion. Perhaps "anxiety alone can define the future" (Cioran). A hypertrophic, invasive today is the companion of an increasingly disquieting tomorrow (...) where* ***proof, without concern, is demanded of science****..."* (Didier Sicard, former President of CCNE, March 20, 2004).

the minority and the intrinsically beneficial nature of knowledge is generally recognised.

And yet, the 20th century marked a turning point in the direction of progressive awareness of the absence of identity between the development of scientific knowledge and the progress of humanity. Need we mention the explosion of the atomic bomb as only one extreme example? As a result, certain scientific discoveries are called into question because of the risks they may generate and concurrently, a climate of mistrust is created that we should attempt to dispel as soon as possible. Consequently, there has been a gradual development of recognition for certain citizen alarm mechanisms to warn society of possible dangers. Yet scientists and physicians and their respective institutions are *a priori* the first to be able to identify an event that could conceivably present a potential danger for human beings and their environment. While they may not be the only ones who can do so, their obvious duty is to bring such an event to the attention of civil society and of the authorities. But it must also be emphasised that confirming or disputing the existence of some dangers may require extensive, and sometimes non conclusive, scientific research.

I-2 Differing expectations by scientists and non scientists: a thirst for knowledge or a thirst for certainty

When he introduced the public for the first time to the theory of relativity in 1919, the French astronomer Charles Nordmann, wrote: "Science is like a clearing in the forest of the unknown. The more science extends the clearing, the closer it brings us to the unknown." In other words, increasing the extent of scientific knowledge and experience does not only reduce the distance between known and unknown, but above all it reveals the extent of the unknown. As scientists well know, an item of knowledge is never acquired once and for all; it is a marker in time and is fated to be modified, complemented and sometimes overturned. Scientists accept uncertainty and know that to drive back its limits does not mean that uncertainty is eliminated[7]. Citizens, on the contrary, to construct their lives, and "decision makers", to define public policies, would like to have the support of a platform of knowledge graced with stability and from which uncertainty has been banished.

The issue of uncertainty is therefore at the heart of any scientific information, particularly if the information has a personal impact and the person who receives it needs reassurance. Demographic studies, for example, evaluate scientifically the risk of developing an illness or handicap on the basis of various data or characteristics (behaviour, obesity, genetic mutation). Such studies establish whether in the population under study, there is or is not a link between a given characteristic and the possible onset and severity of a disease. But the interpretation on an individual basis of this item of statistical information is a complex matter. Special counselling units (genetics, prevention) were set up for this very purpose. And yet, the message conveyed by some companies "selling" so-called predictive medicine, clearly insists on individual risk and "motivates" the public to call on them in the hope of "knowing" a hypothetical medical future.

Increasingly, the authorities are asking scientists to serve as experts in public decision-making processes dealing with risk diagnosis and evaluation and the possible implementation of the precautionary principle. The CNRS (The French National Centre for Scientific Research) Ethics Committee (COMETS), in its report on "Ethics and

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7 "*Science obliterates the ignorance of yesterday and reveals the ignorance of tomorrow*" David Gross, Nobel Prize in Physics 2004.

Scientific Expertise[8], expressed the hope that expert opinions could "become an effective interface between scientists and the various players of life in society: the public at large, institutional and political entities, industrial and economic actors. They could then create dialogues and contribute to the development of civil society's scientific culture and, vice versa, better understanding of society's expectations by the scientific community". However, as COMETS had written in 1996, "scientists are not always or not only experts. They are more than that, insofar as their knowledge, their approach, their questions, go well beyond mere expertise"[9]. Furthermore and most particularly, as Jean-Marc Lévy-Leblond[10], rightly remarked, "the expertise of the few prevents the competence of the many". He also said that "scientific expertise used to camouflage political and economic responsibility is one of the more harmful consequences of the mythification of science".

I-3 Involvement of citizens in scientific decisions and orientations

The accountability of science to society, particularly the bio- and health sciences, would not be a major issue if it did not affect so profoundly the life and environment of human beings. The Age of Enlightenment completed the task of making science sacred, to the extent that it was almost beyond the reach of critical evaluation by the democratic representation. Yet, the image of science in society and the consensual decisions which may be taken greatly depend on the status of the dialogue that can be engaged between scientists and laymen.

For scientific or medical matters to have any real chance of participating in society's decisions and developments, it is of crucial importance that every citizen is given multi-faceted and critical information on these subjects. The "*Centres de Culture Scientifique Technique et Industrielle" (CCSTI*[11]), among them the *Cité des Sciences et de l'Industrie de Paris,* are forums for this dialogue between science and citizens. They facilitate access to, and understanding of, scientific results. However, they are not able to respond to all the needs for discussion and information about science and scientific methods and achievements. Other types of exchange between science and society could be organised.

I-3-1 Estates General

Another kind of constructive dialogue could be organised, in particular when the consequences of scientific and technological decisions are of a political nature: "Estates General", such as those which were organised to prepare for the parliamentary debate on the revision of the French laws on bioethics. Such occasions gain extensive media coverage and enable politicians, scientists, experts and citizens, some of whom are sufficiently qualified in scientific matters to participate in the discussion, to gather together. After frequently meaningful debate, in which the participation of laymen and specialists is sometimes difficult to tell apart, reports are drafted and politicians can make good use of

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8 COMETS report on ethics and scientific expertise (September 2005)

9 Rapport du COMETS sur la diffusion des savoirs (mars 1996) (COMETS www.cnrs.fr)

10 Quoted by C. Granjou: L'expertise scientifique à destination politique. Cahiers internationaux de sociologie 2003/1 n°114. P175-183

11 CCSTIs (Centres for Scientific, Technical and Industrial Culture) were created in the 1970s and were given the task of spreading scientific culture to every kind of audience, young ones in particular. There are now some 30 such centres across France, and they receive about 2 million visitors and 15,000 school classes every year. Three thousand researchers participate in their activities which include discovery, transfer of knowledge outside the school environment and the organisation of discussions between the scientific community and society as a whole.

them to throw light on their own discussions.

I-3-2 Citizen forums

Estates General are similar to the "*conférences de citoyens*"[12], introduced into France some ten years ago, based on the Danish model (called Consensus Conferences) where, since 1987, they have filled an advisory role to Parliament through the Danish Board of Technology. They could be described as an adaptation of the medical Consensus Conferences which are discussions organised by a number of learned societies and which are intended to assist medical decision making. These are mostly organised in the U.S. and in France. The difference, however, is that a central role is given to a panel of "ordinary citizens" ("lay people"), which chooses the themes for discussion, the experts participating and prepares the conference's conclusions and recommendations. Such consensus conferences are always focused on subjects of scientific and/or technological controversy with a powerful impact on society, such as the GMOs, nanotechnology or the use made of genetic data.

This method of participation is based on the fact that a given individual is always "someone else's layman" and that the only important qualification is being an "enlightened citizen[13]. It is supported by the hypothesis, proven by experience, that citizen panels are mature and capable of dealing with sometimes very complex subjects. This is not so much an endeavour to make science accessible to the public ("public understanding of science") as inducing the public to take a more active role in science and its consequences ("public involvement in science"). This format of citizen forums was one of the methods used in the Estates General on Bioethics, together with lively discussions on the Internet and more "traditional" forums.

In some circles, mainly political ones, there was concern regarding a possible blurring of functions between these citizen forums and debate in representative assemblies, French Parliament in particular. These conferences are obviously not designed to act as a substitute for representative democracy; they are intended to throw light on a subject before a decision is taken and to enhance democratic deliberation. Participating citizens are not "representative" of the population as a whole. They are small in numbers and acquire sufficient basic understanding of the subject to enable them to participate in informed and thorough reflection. The superior quality of the considerations and opinions which are generated by these conferences show that motivated laymen are perfectly capable of acquiring information and education, as long as the quality of information delivered is of a high standard, contradictory in nature and pertinent. It is true, however, that setting up citizen panels, in view of their size and lack of representativeness, does raise a certain number of ethical issues, in particular those connected to the possible exclusion of specific categories, age groups, etc.

I-4 A crisis in scientific aspirations

Over the last fifteen years, there has been a drop of 40 to 45% in the number of people wishing to enter scientific callings. This decline is all the more alarming because, unfortunately, it relates to important sciences such as biology, physics and chemistry. The situation is truly disastrous for these disciplines. Mathematics are also in decline but less dramatically at 25%. The figures for this disaffection cannot be interpreted simply or

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12 See, for example: http://www.rezoscience.ch/rp/sc/outils/glossaire1.html or for a specific theme: http://www.meetingmindseurope.org/france_site.aspx?SGREF=159

13 Hearing of Marie-Agnès Bernardis, *chargée de mission* at the *Cité des Sciences*, April 23, 2009

univocally[14], but it would appear that while the French public continues to state its faith in the sciences, many young people find the study of fundamental science very unattractive — almost repellent — and prefer to turn to more applied disciplines and/or professional channels.

The reasons for this disinterest are numerous. One of them is clearly financial and current efforts to upgrade researchers' salaries at an early stage, i.e. when they are preparing their doctoral thesis, and to rehabilitate the "docteur ès sciences" title so that it can rival with that of engineer, will probably help to enhance the attractiveness of scientific careers. Nevertheless, and this is one of the issues with which we are concerned here, scientists sometimes do have an unfavourable image, perhaps connected to lack of information concerning the work they do. As the 2002 Porchet report noted: "It is up to members of the scientific community and those researchers who also teach to explain how they work and how academia is organised"[15].

I-5 New kinds of pressure on scientists

Pressure on researchers keeps increasing as evaluation procedures grow more rigid and as quantitative as possible. Such pressure is particularly strong on researchers at the start of their career, but their more senior colleagues are not exempt. Apart from the impact factor of a journal, quantitative criteria include the number of times and how long an article is quoted, etc. Bibliometrics are a tool used more and more frequently to measure a researcher's productivity. It has become one of the essentials, but — and no one disputes this — it must corrected and/or completed by direct scientific evaluation of the quality of work concerned. A redefinition of the criteria for evaluation would appear to be urgently required.

Although we are not claiming any cause and effect between such pressure and unacceptable behaviour, the ambition to the first to publish in an advanced field of research can lead, as the media have pointed out, to "enhancing results", or even "organised fraud" or "mendacious publication", all of which have a devastating effect on the image of science in the eyes of society.

I-6 Financial issues

Any research needs financial backing. It may originate from various sources: public (central government or regional authorities; or private (foundations financed by donors or industry). For any particular project, there may be several sources. Procedures for obtaining financing include, more often than not, competitive selection based on a scientific evaluation of projects. Scientists who have raised funds do have some obligation to their backers. They normally communicate their results, provide information on the advances they have contributed to and demonstrate that funds have been used to good effect.

But they may also be tempted to publish results prematurely or embellish possible outcomes so that their audience, current or possible future sponsors, are suitably impressed. This problem is particularly acute when financing is provided by donors who are likely to be attracted by the mirage of applications that the current status of research cannot possibly, in fact, predict with certainty. Extreme vigilance is not always exercised in screening scientific communication linked to, or preceding, calls on public generosity.

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14 « *Attractivité des études scientifiques : crise de foi, retour d'affection et main invisible du progrès.* » Working document, February 19, 2006, Olivier Las Vergnas : http://enviedesavoir.org/stock/desaffection42.htm

15 Maurice PORCHET (2002): Report for the Minister of Education on young people and their attitude to scientific education: Les raisons de la « désaffection » ; un plan d'action.

First in line for receiving scientific information are the media, specialising in scientific matters or addressing the general public, journalists on the lookout for scoops or news that could enhance their employers' media coverage and financial prosperity (reviews, written press, television, etc.). Scientific publications, like the rest of the media, are usually business enterprises. Despite the marked improvement in the scientific background of specialised journalists and the laudably high quality of the scientific pages in some non specialist newspapers, the fact remains that making an important announcement has a direct impact on the number of copies or subscriptions sold. Obviously, such outcomes have a decisive effect on the way in which the scientific fact is presented to the scientific community or to society as a whole and the situation may generate preferential connections, or even collusion between certain journalists and certain researchers. It may go as far as creating links of subordination between researcher and journalist. It can also lead to injustice with certain researchers having less access to the media than their fellows.

The editors of scientific journals are therefore in a position of control, not just over "passing fads", but also over the circumstances in which society will be receiving a message and can react to it. Since scientific publication is increasingly the main criteria for the evaluation of scientists, their team and their laboratory, as well as the institutions which house and finance them, there is a risk that scientific strategies are perhaps not so much piloted as at least influenced by the "big media magnates", from the scientific or non scientific world of journalism, whereas they should in fact merely be involved as observers.

The financing of research by the private sector, be it industry or associations, may also create links of subordination. Contracts between public sector research teams (CNRS, INSERM, universities, etc.) and private financiers usually include clauses to protect against major problems (researcher's freedom to publish, for example), but they cannot control some of the more subtle links. Some scientists are, for that matter, hostile to seeking private sources of finance since they consider that such practices are at a double disadvantage: having fundamental research masterminded by its possible applications and the creation of a link of subordination between researchers and economic players.

II – Specificity of the transmission and reception of scientific and medical information

II-1 Transmission of information within the scientific and medical community: communication between scientists

Scientists make the results of their work public through oral presentations — generally in English — in conferences, where they are exposed to criticism from their peers, and/or in print in scientific journals, also in English, which are subject to rules of evaluation and selection, all the more severe when the journal is highly regarded. A publication's impact factor is the subject of painstaking calculation and is regularly updated. Reviews such as *Nature*, *Science* or *Cell* have the highest impact factors. Increasingly, publication in one of the leading journals has important consequences for a researcher: peer recognition, easier access to financial support for future research, personal bonuses, scientific awards, etc.

The primary filter for the evaluation of results is activated before their publication. Several experts, generally anonymous, are tasked by the editorial team to examine the research protocol, the methods of analysis, the results themselves and the exactness of

the conclusions: this is known as "peer review". But the essential validation of results, that which confers on them in the long term true scientific worth, is passing the test of repeatability. To progress from the status of important data to that of proven scientific breakthrough, results must be repeated independently by another laboratory. Such validation can only take place once the results of the first research have been published. When the data is not confirmed, it is to be noted that, regrettably, despite the disclaimer being public, it never attracts as much media attention as the initial publication. It is also to be deplored that the negative results of research are not made known to the general public because it is difficult to publish them.

Subscriptions to scientific journals, either in hard copy or electronically, are very expensive so that those who are not too well off (for instance scientists in countries of the South or small universities lacking endowment, etc.) are denied the information. In reaction to these financial constraints and restrictions, the Nobel prize-winner Harold Varmus, inspired by the example of free sharing of recent data by physicists, and spurred on by the outstanding acceleration of biological research, advocated the setting up of what are called today "open sources" and made it possible, in spite of opposition from scientific publications, for new forms of scientific dissemination to see the light of day[16]. These new on-line methods of publication, together with the creation of new tools for that purpose, also make it possible to evaluate the impact of an article on the scientific community without delay. In an Opinion published in 2007, the CNRS Ethics Committee, recommended a diversification of public and private methods of scientific publication[17].

II-2 Transmission of scientific and medical information to society

II-2-1 Language limitations

Scientists use very specialised technical language which can give rise to misunderstanding or incomprehension.

Science is divided into domains and sub-domains, themes and sub-themes. In biological and medical research, language used by specialists in each sub-domain has become ever more specific, to the point that it is opaque for other scientists, and *a fortiori* for the general public. The vocabulary, not to say the *jargon*, particular to each scientific domain cuts it off and isolates it. In the circumstances, it is hardly surprising if the man in the street finds it difficult to comprehend the exact scope of a scientific discovery, even though he has an idea that it may have repercussions, perhaps on his own lifestyle. As a result, popularization is of crucial importance.

It is true that some concepts and data are easier to explain and understand than others. At first glance, this is the case for biology and particularly for health-related subjects which, more than other sciences, are of direct concern to the ordinary citizen. However, biology and medicine, particularly since they have turned "molecular", have become sciences which are no longer contained within the confines of "description" and have reached the "analysis of mechanisms" stage. To gain a thorough understanding of

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16 Interview of Harold Varmus by Richard Poynder, June 5, 2006: "I believe that science is one of those activities that improves the state of the world," replies Varmus, "and once you realise how important publication is in the series of acts that constitutes the doing of science, and once you understand the incredible transformation of that publication process that the Internet, and software, and the whole digital world, now promises it is hard not to be pretty passionate about trying to make that part of the scientific universe work more effectively." (http://poynder.blogspot.com/2006/06/interview-with-harold-varmus.html)

17 COMETS Report on « Reflexion éthique sur la diffusion des résultats de la recherche » (Ethical considerations regarding research results) (March 2007).

them is now as difficult as for more abstract sciences such as particle physics or astronomy.

Scientists and all those who play a part in the transmission and dissemination of scientific and medical information are confronted with the huge gap, which is constantly becoming broader, between everyday and scientific language. When scientists are alone able to understand completely the information they wish or are required to disseminate, they have to rely on modesty and lucidity: the vocabulary they use is crucially important. The extreme variability in the level of scientific and technical culture of the man in the street must be taken into account. It is up to scientists to adapt and use ordinary language and avoid using specialised vocabulary in their communication. And all this must be accomplished without falling into triteness and approximation.

It is important to emphasise that writing and speaking about bioethics regularly brings us face to face with the limits of language. We all know the extent to which expressions such as "gestational surrogacy", "organ donation", "supernumerary embryos" and even "palliative care" or "therapeutic cloning" were the subject of spirited discussion, although they are now used in texts of law.

To sum up, for scientific communication to be as clear and effective as possible, it is important to weed out ambiguities to the fullest extent and to seek the most appropriate language, even though we know that this is bound to be an asymptotic endeavour.

II-2-2 Difficulties linked to differences in basic scientific education

The CSA poll quoted above[5] revealed a contrast between the generally good image people have of science and their lack of interest in the subject: 47% only of the people polled professed any interest in scientific matters. And yet, since the 1980s, at both national and regional level, the Ministry of Research[18] in particular, Parliament and also Regional Authorities have conducted a very energetic policy in favour of scientific and technical culture. A number of institutions (Cité des Sciences, museums and scientific theme parks, etc.) were either bolstered or created. A very recent initiative, the creation of a new public institution for the dissemination of scientific and technical culture, is much to be applauded ("Universcience", which brings together the competence of the *Palais de la Découverte* and the *Cité des Sciences et de l'Industrie,* with the task of propagating a taste for science within the community, of giving science a place at the heart of society and to help everyone gain a better understanding of the world we live in and the changes it is undergoing).

Although scientific and technological education is largely recognised as being a major social and political challenge, average knowledge levels are still too low. A very large majority of secondary school pupils view scientific subjects as difficult, if not downright forbidding. And yet, the scientific curriculum is still considered to be representative of excellence in our system of education, in particular because of the specific capacity for analysis and reflection that it provides. But alas, it is not the route followed by the majority and pupils who choose other curricula will be that portion of the public whose basic scientific education will be too limited for a good grasp of scientific information on the advances of scientific research.

Is this situation due to the intrinsic difficulty of scientific subjects, or is it the way in which they are taught; or perhaps the school syllabuses themselves generate such generalised demotivation? Many associations are working on cultivating a "taste for science", an essential requirement if future citizens are to consider science favourably. In

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18 Jean Pierre Chevènement, Minister for Research 1981-84 and Hubert Curien, Minister for Research, 1984-86, 1988-93.

June 2000, the Minister for Education praised a scheme called *'La main à la pâte'* (Hands On), an excellent initiative fathered by Georges Charpak and the French Academy of Science, with the support of the *'Institut National de la Recherche Pédagogique'* (National Institute for Pedagogical Research) and announced a plan for the renovation of scientific and technological education but, so far, this has not been implemented.

We are therefore at a time when every effort should be made to ensure that a majority of schoolchildren, after receiving basic education (primary school), are aware of how scientists work and, enlightened by the history of science, understand that progress is the result of multiple scientific adventures, the consequences of which were initially unpredictable. Scientific teaching in schools should describe the sciences as a fascinating intellectual adventure at the very heart of the human odyssey.

II-2-3 Means of communication, the 'medias' and the Internet revolution

CCNE had already underlined in 1995 that "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"[19]. The Opinion emphasised that the logic of communication for journalists differs considerably from that followed by scientists. Be it reported in the daily newspapers or other media, factual "objective" data is often obscured by more journalistic considerations. Unfortunately, the advent of the Internet has not modified this state of affairs. On the contrary, it may have fuelled the confusion between too much information and a sufficient degree of knowledge.

The term "medias", habitually used to designate those who transmit information, includes scientific journals, publications for popularising scientific information, the general press, radio, television, the Internet or the CCSTIs. Each of them has a function of its own, a particular public, constraints and its specific position in regard to researchers and in the relationship between science and society. It is, at least in part, via such media, that scientists make the results of their research known to the world at large. An article published in the general printed press on the subject of new results can be based on an interview with the scientist concerned, or on a press release issued with the publication of such results — the release being the work in some cases of the scientific review in which the results are published — and/or the institution (CNRS, INSERM, university, etc.) in which the researcher works. In none of these cases, however, does the scientist fully control the way in which his or her work will be reported by the journalist, even if, as is quite often the case, the journalist asks the researcher to review the article. In radio and television, generally a few seconds out of an interview with the scientist are broadcast. This is a perilous exercise for the scientist because, out of context, the two or three sentences which are extracted can distort the meaning of the results.

Researchers are not trained to cope with the difficulties and pitfalls of these methods for the publication of their results. Should universities consider including a course on scientific communication to their programme of study? Over the past ten years or more, several French universities have organised master's degrees to train for this mode of communication. Schools of journalism also give such training and the university courses aim to complement science degrees with tuition on the concepts and techniques particular to the various medias and pedagogical tools for communicating with various audiences. It seems likely that better cooperation between researchers and the media would help to improve the efficacy of such communication.

The written press, radio, television and now the Internet are all developing, each in

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[19] CCNE Opinion N°45 on Ethical questions arising from the transmission of scientific information concerning research in biology and medicine.- May 31, 1995

its own format, a mode of communication based on the latest trends and "scoops" which interferes with their role as mediators between science and society, in a way which very few of them are able to break free of. The corollary of this *de facto* situation is the creation of a system of recognition by society which can go as far as turning some scientists into "stars", sometimes far more than would be earned by peer-recognition. Some of these scientific stars are excellent communicators, which can only be a reason to rejoice. However, a thirst for public recognition inhabiting some others has led to a few highly publicised and unfortunate incidents which were extremely harmful for the image and the representation of scientists in the eyes of society. Taking advantage of the public's growing appetite for scientific novelty (possibly to exacerbate its fears), the mass media is now open to the presentation of preliminary results, the pertinence of which cannot be assessed by a lay audience for the domain concerned. Until recently, this was only allowed to happen for particularly important scientific breakthroughs.

An increasing number of scientific journals, both generalist and/or specialised, communicate the contents of articles to press agencies; this does not absolve the authors of such articles from their responsibility for such announcements. The responsibility is today distributed between scientists — personally — and their institutions which, ever more frequently, participate in the media storm engulfing in particular biological and medical subjects. Furthermore, communicating an excess of scientific facts to, not just scientific journalists who are able to transform some of them into information, but also to mass media who pass them on unprocessed, may not put scientists or their institutions in a position of strength as regards the media. On the contrary, it can make them media dependent.

In the last few years, we have been witness to extensive changes in scientific and medical communication, due to the generalisation of access to data networks via the Worldwide Web. The Internet, offering as it does an abundance of information on every subject, provides the illusion of universal knowledge accessible to everyone and creates a thirst for quickly-acquired knowledge. But what it does not do is make apparent the need to develop a critical attitude. As a result, doctors are sometimes faced with patients who are no longer naive, but are not correctly informed.

The government has taken steps to supervise more effectively the medical sites and forums which flourish on the Internet. Hundreds of health-related sites in France offer more or less objective and verified medical information. To counter such abuse and "ensure that health-related information given to patients is as complete and reliable as possible", Parliament voted in March 2009 an amendment to the law on "Hospitals, Patients, Health and Regions", inviting such sites to show on their home page their link with institutional sites: national health insurance establishments, French Health Products Safety Agency (AFFSSAPS), or the French National Authority for Health (HAS). This is a complement to the system set up in November 2007, under HAS supervision[20], of a voluntary certification process for health-related web sites which has proved to be hugely successful: over 700 sites meeting the criteria have been awarded certification[21].

What is beginning to exist for the so-called "health" sites, is not extended to the large number of "encyclopaedias" emerging on the web. Although in the absolute, if scientific data is universalised, this can be viewed as a good thing, the validation required to turn it into scientific "information" is missing and would require considerable investment

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20 http://www.has-sante.fr/portail/jcms/c_334538/la-certification-des-sites-internet-sante

21 The Health On the Net Foundation is a benchmark as regards the promotion and availability of on-line information on health and medicine, as well as on its appropriate and effective use. It defines a code of conduct (HONcode). When a website conforms to the code, it is allowed to display the HON logo on its home page (http://www.hon.ch/index_f.html). The foundation has signed a partnership agreement with the French National Authority for Health (HAS).

on the part of the scientific community.

II-2-4 Challenges particular to the transmission of medical information

Scientific breakthroughs followed by applications modifying our life environment reach us through various perception filters that sometimes do not leave us much leeway for detachment and freedom of appreciation. When they are related to the biosciences, health in particular, the filters are shattered by contact with our innermost feelings.

Among the specificities of communication concerning the biological and medical sciences, one must be addressed particularly in view of its considerable ethical repercussions, i.e. perception at a personal level. The media-conveyed results of biomedical research can give rise to groundless fears and hopes, and elicit unreasonable behavioural changes. Another specific characteristic which applies to the life and health sciences to an even greater degree than to other domains, is the astonishing speed with which is acquired new knowledge that may disprove earlier data. One of the fundamental challenges of communicating and disseminating medical information is therefore to convince the public that data which has been the subject of formal review, correction and even public debate can be emended by the progress of knowledge.

Many people may feel concerned by a new scientific issue such as global warming. In this particular case, any solution will be essentially collective, although everyone can make an individual contribution. In the life and health sciences, the announcement of a new event, such as the serious mad cow epizootic outbreak and its human consequences, or that of any other epidemic, primarily affects us collectively. But in the event of communication on the potential dangers of mass vaccination, the situation is different since it is at an almost exclusively individual level that the information is received. Similarly, the announcement of a new genetic test is pertinent at the most intimate personal level. The information provided in each of these examples therefore responds to very different challenges.

Citizens need to feel they are respected and properly informed of the true therapeutic prospects of the great scientific breakthroughs that hit the headlines. They are entitled to clear information when dangers such as epidemics and pandemics emerge, and also to be sure that they will be consistently kept informed should an event occur which concerns them closely, or even remotely. The dialogue between doctors, scientists and experts in the life sciences on the one hand, and citizens on the other, should aspire to more clarity, simplicity and even humility. This is a necessary condition if society is to be spared the build-up of false hopes, in particular as regards curative or preventive medicine.

A special point must be made regarding crisis situations — be they related to health, to the media or to natural disasters — during which scientists and doctors are asked to inform the public. Assuredly, information is not delivered in the same way in an emergency (one minute on television) and at other times. Communication is all the more difficult because, more often than not, the subject is a hypothetical or confirmed risk of direct concern to one section of the population (multiple sclerosis, vaccination against hepatitis B, a cluster of cancers in a school, etc.) or the population as a whole. Nevertheless, it is in the midst of a crisis that the public wants scientific information and that it becomes aware of the issues and seeks to comprehend fully the impact of the information. The health sector could benefit from the kind of analysis that has been made in other domains, industry in particular, with a view to gaining more insight on the specificities of communication in a time of crisis.

RECOMMENDATIONS

The transmission by researchers of scientific information to the public has recently undergone a great deal of change, in particular as regards speed and the number of forms of communication, essentially as a result of the electronic revolution. Society has high expectations of science, but there remains nevertheless, a certain degree of discontent, sometimes mistrust, and above all an intense need of information in the presence of breakthroughs that are known to have an impact on personal wellbeing or that of society in general. In the light of this situation, CCNE makes the following recommendations.

Make perfectly clear to citizens that the validation of scientific information is of critical importance

It is important for the public to be certain that the information it receives via various media is validated. But no one is more qualified than the researcher concerned to validate scientific information.

The first level of validation for new information takes place before results are published in the scientific journals. The public needs to know that fact.

The second level occurs when the original information is published, i.e. transmitted to the public, scientific or lay. A specialised scientific public is capable of reading an article describing a scientific discovery or breakthrough, but a scientific public which is not as familiar with a given subject may find it difficult to understand. The scientific journals provide a certain form of popularisation for that public. Journalists working in these scientific journals are generally extremely capable.

When the information reaches the general public, a new line needs to be crossed. The general public needs a translation, a complete form of popularisation. In this instance, it is most desirable that the information transmitted, generally through a journalist, is validated whenever possible by the researcher concerned as regards the implications and importance it may have for the public.

The growing inclination on the part of certain scientists and their institutions to disseminate a large number of results to the public via the general media should be tempered by an appreciation of the level of interest that such results may have for society as a whole. Close and constant exchange between scientists and the media, as well as precise scientific validation of the facts being reported, enable media translation to be as rigorous and respectful of the context in which the scientific fact becomes meaningful. **CCNE highly recommends such exchanges between scientists and the media.**

Since information is increasingly available from websites, public use of good quality sites must be encouraged, in particular via information on how such sites are "validated".

An important fact, namely that the validity of an item of information can be revised or modulated after new results are acquired, must also be made public. More publications should be devoted to reporting on modifications or amendments to results.

Urge and encourage scientists to improve their communication skills

- **Urge and encourage scientists to increase their involvement with the validation and transmission of scientific information to society.** Scientists and/or

physicians are not experts in communication, but it is absolutely essential that they should be directly involved in the validation of scientific information. For doctors, such validation requires, in particular, some degree of continuing education.

It would also be well if scientists and doctors were regularly involved in the transmission of information and in discussions on the impact of science on society. At a time when society is very eager for information, motivating scientists to participate in such debates requires that this activity be recognised by evaluators as an integral part of their activity. It would also be essential that scientists, when they speak in public, clearly distinguish between what is known to science, what is currently hypothetical and what represents their own personal views. Making a very clear distinction between what one knows for a fact and what one supposes is crucial. One of the first tasks of popularisers is to set out this difference very clearly. Competent popularisers are also those who are able to set a scientific or medical breakthrough in its proper context, who take the trouble of relating its history and underlining its importance while steering clear of any exaggeration under the influence of media pressure or of a thirst for fame.

- **Encourage a greater sense of responsibility in the scientific community, particularly on the part of those who, when speaking to the public at large, might be tempted to exaggerate the significance of their results. Alert scientists to the need for the greatest intellectual honesty and rectitude when they participate in media fund-raising campaigns and calls on public charity.**

- Make sure that scientific breakthroughs are not divulged prematurely.

Encourage action to raise the level of basic scientific education.

- **Raise the level of interest in science generally**[22]. A taste for discovery is one of the characteristics of childhood curiosity[23], but it tends to disappear as they grow older. The Gago report on the situation in Europe[24] mentions surveys showing that by the time they leave primary school, half of European children believe that science and technology are not within their grasp. This proportion rises to 90% at the end of secondary school and increases further as they pass their final secondary education exams, even for those who are following a scientific curriculum. To promote scientific and technological education, these disciplines must be open to the broadest possible school population, whose interest and proficiency in science and the scientific mindset have been aroused since elementary school. The Rocard[25] report to the European Commission made a study of the measures that should be taken to raise more enthusiasm for the sciences in young people. It sets out recommendations regarding the need for collective action to improve the teaching of science and the steps to be taken at various local, national and European levels. CCNE supports these recommendations.

- **Encourage the teaching of science at an early age:** teaching science in primary and secondary school has a lasting influence on the average scientific competence of the population and therefore on its capacity to understand the language spoken by the scientific community. In order to achieve this, the scientific curricula should

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22 "*As long as researchers are not familiar heroes of films and television series, as long as Bernard Pivot sees Claude Hagège and Nicole Le Douarin as aliens from outer space, as long as Philippe Sollers has not investigated the fate of cloned ewes and Michel Houellebecq is alone in celebrating elementary particles, science will not be on our daily agenda".* Françoise Tristani-Potteaux, Journal du CNRS, June 2001

23 Charpak G., Léna P., Quéré Y. L'Enfant et la science. O. Jacob, 2005

24 M. Gago. *Europe needs more scientists*. Report to the EU, 2006.

25 Science Education NOW: A renewed Pedagogy for the Future of Europe. M. Rocard, P. Csermely, D. Jorde, D. Lenzen, H. Walberg-Henriksson & V. Hemmo. 18/06/2007.

be reviewed, supplemented and made more attractive. In the medium term, such action should serve to increase the number of young people who are keen to enter into higher education in scientific disciplines, particular in biology and medicine. The purpose of such action is not promoting the teaching of science to the detriment of other educational pursuits, but to increase the integration of science within other disciplines (history, sociology, etc.). Science, however, should be introduced as an integral part of general culture at a very early stage of schooling and also in the training of the future elite, be they political leaders, economists or journalists.

- **Promote the teaching of two very educational subjects, the scientific approach and the history of the sciences.** Reverting to scientific education based on learning the history of the sciences and on scientific methods (concepts and experiments) would provide a greater number of students with a solid foundation for reflection leading to improving their understanding of scientific novelty.

- Encourage research organisations and institutions to open their doors to the public at large. The major research organisations and institutions, such as CNRS, INSERM, CEA, INRA as well as the *Institut Pasteur*, the *Institut Curie*, the *Académie des Sciences* and the *Académie de Médecine* (who are all beginning to take this path), would enhance their visibility and their level of communication if they were more open to the public at large, in particular they could make their journals available to the public and invest in some degree of popularisation of their activity. Opening out to the public in this way would certainly help to curb the shortfall in scientific vocations.

- Increase the number of scientific programmes on radio and television. The number of scientific and medical broadcasts on public radio and television is currently very low: the importance of such programmes is all the more worthy of emphasis and support since public audiovisual information is much more independent of advertising and audience measuring ratings than its "private" counterpart.

In conclusion,

Society expects a great deal from science and wishes to be adequately informed of scientific matters. The Internet revolution, coming on the heels of the audiovisual revolution, is overwhelming us with information, but this excess has not managed to eradicate the enormous gap between the scientist or the doctor and the citizen or the politician. Indeed, it has been said that this lack of understanding seems to be increasing as scientific progress increases its pace. It is therefore more important than ever that the scientific community remain in constant touch with the expectations of a highly varied civil society, composed of citizens some of whom are only occasionally interested in scientific issues and therefore need to be informed and made aware of their significance, but also of those who, while they are not scientists, have a real intellectual interest in scientific matters, or again those who are interested in science for specific personal reasons, such as ill health or infirmity.

CCNE hopes that, remaining fully respectful of freedoms — for individuals and the media alike — the communication of scientific and medical information to society can take place in a spirit of complete trust between scientists and society, as well as between scientists and the scientific and general media. It proposes several recommendations, some of which do no more than relay recent private or public initiatives, that could help in the medium term to renew the interest for scientific careers so essential to the future of this country.

Paris, February 4, 2010