

Infectious diseases and governance of global risks through public communication and participation

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Summary. In recent years a succession of health emergencies connected with the threat of new, possibly global, infectious diseases has stimulated the attention of the mass media, the scientific community, and international public opinion, setting a tough test for the institutions whose job is to manage the risks. On the basis of experience in the fields of AIDS, BSE, SARS and bird flu, this study discusses the strong and weak points of governance procedures for health risks. In particular, the paper illustrates how risk management can be improved by adopting practices and procedures which actively involve the public in dealing with the emergency, by taking a transparent and accessible approach to communication with the public (including the provision of information about the risks) and by fostering the unrestricted exchange of scientific knowledge among researchers. Lastly, the text shows how the analysis of these themes provides starting points for understanding the crisis in the current relationship between science and society.

Key words: infectious disease, risk governance, risk communication, public participation.

Riassunto (*Malattie infettive e pratiche di comunicazione e partecipazione pubblica nella governance dei rischi globali*). Negli ultimi anni il susseguirsi di emergenze sanitarie correlate alla minaccia di nuove malattie infettive dal carattere globale ha catalizzato l'attenzione dei mass media, della comunità scientifica e dell'opinione pubblica internazionale, mettendo a dura prova le istituzioni preposte alla gestione del rischio. In questo lavoro sono discussi i punti di forza e di debolezza dei processi di *governance* del rischio sanitario a partire dalle esperienze maturate nei casi di AIDS, BSE, SARS e influenza aviaria. In particolare, si illustra come la gestione del rischio possa essere migliorata favorendo l'adozione di pratiche e strumenti partecipativi capaci di coinvolgere attivamente il pubblico nel fronteggiare l'emergenza, una comunicazione pubblica fondata sull'accessibilità e la trasparenza delle informazioni sui rischi, il libero scambio di conoscenze scientifiche fra i ricercatori. Infine, si mostra come l'analisi di queste tematiche offra spunti di riflessione per comprendere la crisi dell'attuale rapporto fra scienza e società.

Parole chiave: malattie infettive, *governance* dei rischi, comunicazione del rischio, partecipazione pubblica.

INTRODUCTION

The last quarter of a century has been marked by outbreaks of new infectious diseases which – from AIDS to the human variant of BSE, from SARS to bird flu – have been seen as real global threats capable of breaching geographical, economic and social barriers in a very short space of time. Yet, at the end of the 1960s, in a widespread climate of optimism about technological developments, medical sciences seemed to be close to defeating infectious diseases once and for all. In 1969, US Surgeon General William H. Stewart announced, “War against infectious diseases has been won”.

Moreover, with the perfection of penicillin during the Second World War, western medicine seemed to have the knowledge and the tools necessary to con-

tain the spread of epidemics (hygiene procedures and vaccination) and to treat infections which had already broken out (antibiotics). From mysterious, unavoidable disasters one could not prevent or cure, infectious diseases had been transformed into health risks that could be fought and controlled by the correct management of pharmaceutical techniques, health policies and responsible individual behaviour [1]. New drugs and mass vaccination policies had drastically reduced the effects of polio, the most feared infectious disease of the age. And when, at the end of the 1970s smallpox was eradicated, western medicine was convinced that the days of infectious diseases – *all* infectious diseases – were numbered and that mankind would soon be freed from the nightmare of epidemics.

But then, on 3 July 1981, the *New York Times* published the first news of an unknown and mysterious illness which had been discovered in several dozen homosexuals in the United States: AIDS had arrived, sneering at the enormous strides made by medical science. If, in the early days, the disease seemed to be confined to specific risk groups (gays, drug addicts and haemophiliacs), it was very soon evident that AIDS recognises no class or racial distinctions, no sexual preferences.

It was precisely the *global* nature of AIDS, the first massive-scale epidemic modern mass media had ever been able to report directly right from the outset, that focused western attention on an illness that could reap its victims just as well on the hills of San Francisco as in the brothels of Bangkok, in the City of London or the Brazilian *favelas*, until, in the end, it shook our lives and our social relationships to the roots [2].

AIDS cannot simply be categorised as one of the many “natural” disasters which assault the Third World every so often, like drought or famine: catastrophic as they are, they cannot *make history*, they cannot influence our society at a deeper level [3]. AIDS has stirred the conscience of western societies, pointing out our vulnerability to infectious diseases: “*AIDS is not one of the numerous pathologies that affect the poor, which – we claim proudly – have suffered a historic defeat at our hands, conquered by our civilisation with its clean water, sewers and chemically manufactured drugs. AIDS is among us. It has created a bridge between our conscience and the sufferings of the southern hemisphere* [2].”

Today it is estimated that the number of people affected worldwide has reached almost 40 million. In 2006 there were 4.3 million new cases (65% of those in sub-Saharan Africa) and the number of AIDS-related deaths was almost 3 million. The phenomenon is increasing continually in the developing countries and expanding its hold firmly in Eastern Europe and Central Asia. But the richer countries are not spared: in 2006, 65,000 new cases were diagnosed in North America and Central/Western Europe, bringing the number of people with HIV to over two million. Despite the fact that, since 1996, antiretroviral drugs have made it possible to treat (but unfortunately not cure) the disease, western medicine still does not have a vaccine and, to stem the epidemic, can only rely on preventive measures based on hygiene procedures and prophylactic measures.

In a way, AIDS put an end to an illusion, reawakening awareness in a world where infectious diseases cannot be defeated because the agents that cause them mutate continually, adapting to an environment which, in its turn, is also continually changing, at a rate which we ourselves help to accelerate.

Paradoxically, our modern lifestyle has provided new ways for viruses to spread: overcrowded megacities, air conditioning, easier mobility of goods and people, lifting of restrictions on sexual practices, injection of drugs, transfusions and organ transplants,

endangered natural ecosystems, an average rise in global temperatures, intensive farming of animals which may act as incubators for new viruses.

Thus, since the mid-1970s and coincident with the appearance on a global scale of these social and environmental changes, along with AIDS, another thirty or so previously unknown contagious or infectious illnesses have been identified, including Ebola, Lyme disease, new forms of hepatitis and the human variety of BSE. Unfortunately, to these we must add the surprising return of diseases considered to be marginal, such as malaria, tuberculosis, cholera or yellow fever, all of which can strike in regions that were thought to be immune until a few years ago; and once again the main reason is social and environmental changes, not least the effects of global warming [4].

Invisible, impervious to frontiers, with possible long-term damaging effects and difficult to contain once loosed, infectious epidemics are seen as global threats capable of eluding our ability to control them, of provoking a crisis of technical and expert knowledge, of arousing sporadic attention amongst the mass media and kindling public debate in the so-called “risk society” [5]. All elements which contribute to making infectious illnesses a tough challenge for those whose job it is to manage the risks and who, as we shall see, treat communication and participation as central to that challenge.

SARS: SHARED KNOWLEDGE AND TRANSPARENT COMMUNICATION

The 21st century has made another addition to the depressing list of new infectious diseases: SARS (severe acute respiratory syndrome), an atypical pneumonia caused by a coronavirus which, in 2003, almost gave half the world’s health organisations heart failure, with a final victim count of more than 8400 cases and 812 deaths in 30 countries [6].

The SARS epidemic prompted the World Health Organization (WHO) and the international scientific community to implement a health risk management strategy which, by drawing on the sometimes unhappy experiences of the past, aimed at transparency and the sharing of information; an action which, in our opinion, established a benchmark for more effective risk communication.

On 15 March 2003, the WHO put out a warning for travellers and, for the first time, the name SARS appeared: it had been chosen by communications experts in Geneva to be as neutral as possible, a move dictated by the need to try and avoid errors like those committed earlier during the AIDS affair. At first that disease had been christened GRID (gay related immunodeficiency disease), a name that was doubly unfortunate because it implied that the risk only affected gays – burdening the homosexual community with another social stigma – and inducing heterosexuals to believe, wrongly, that they would be immune to the sickness.

The risk was global and the WHO gave a global response in the form of surveillance and research. Immediately, on 15 March, they set up a network of 11 laboratories in 9 countries (which would be joined by 2 Chinese units) modelled on the existing Influenza Surveillance Network. The aim was to enable researchers to exchange specimens and information freely.

The WHO's strategy for communication with the public and the mass media on the SARS issue relied on total transparency: a website with real-time updates and a 24-hour switchboard for journalists and anyone else who might want information on how the epidemic was developing.

Results soon began coming in from the scientists. Thanks to cooperation between the research laboratories (cooperation organised at the very time when the major international scientific journals had decided on self-censorship of any biomedical information that might be used by potential bioterrorists) [7], the SARS coronavirus was isolated in only two weeks. By way of comparison: HIV was not discovered until two years after the first appearance of AIDS; the reasons for the delay were not so much technical as the fierce competition between the research teams led by Luc Montagnier and Robert Gallo who each wanted the credit for the discovery (and to enjoy the associated royalties for the diagnostic tests that would ensue) – the rivalry led the contenders to hide any progress in their discoveries about the virus from each other until, in 1987, a “political” *ex equo* agreement was reached with a handshake between Ronald Reagan and Jacques Chirac. To return to SARS, it took another two weeks to sequence the coronavirus genome that causes it. By July the epidemic was under control. However, even today, there are no specific vaccines or treatments for the disease.

As far as the SARS risk communication strategy is concerned, the WHO's choice to rely on total transparency of information was decidedly innovative. Just think, by contrast, of the reticence of the Chinese authorities at the start of the outbreak, or of what happened earlier with mad cow disease, when the British Government spent almost ten years doing nothing but deny there was any risk to human health, ignoring the alarms raised by the scientific community and sweeping any information that might worry the public under the carpet.

Even so, there is disagreement over the effectiveness of the measure. Many observers criticised the WHO for making too great a fuss about SARS at the risk of creating a public panic over a health threat which, in the end, turned out to be relatively minor.

In our opinion, these criticisms are unfounded. Difficult though it may be to quantify, the risk that SARS might have turned into a pandemic could not be excluded, far less kept hidden. The first rule of risk communication, though often disregarded, says that the existence of a risk must never be denied because “denial of risks is one of the main reasons why they appear, grow and thrive” [8]. In the first place,

because we live in an information society where, if a risk exists, it will soon become public knowledge; in the second place, because when we discover something being hidden from us we automatically suspect that the danger is more serious than the authorities are inclined to admit. Therefore, as the international literature on risk communication has by now demonstrated fully, and as the WHO seems to have understood very well, it's not bad news in itself that increases panic but, on the contrary, “panic that increases when information is hidden or only partly revealed” [9].

Population studies on reaction to emergencies have shown that in fact collective panic is quite a rare occurrence, restricted moreover to a few cases where, in the absence of any reliable authority that could point to a solution, the people involved came to feel they were “trapped” [10]. Historic research has shown that even during the 1918 Spanish Flu epidemic, which comparisons often use as the worst-case scenario, people did not panic but reacted with a sense of social responsibility, intelligence and mutual support [11].

As the lesson given by the mad cow scandal has finally, and typically, shown, admitting we were wrong when it's too late leads inevitably, and sometimes irreparably, to a loss of trust in the authorities responsible for dealing with the emergency. And if, by some unfortunate chance, the WHO were obliged to face a global epidemic, the last thing it could afford would be to lose people's trust. Without trust, any message addressed to the public with the aim of containing the spread of the epidemic would go unheard or unheeded, no matter what the nature of its content [12].

BIRD FLU: TRUST AND UNCERTAINTY

No one knows whether we'll have to face a new SARS epidemic in the near future. Meanwhile, surveillance today is concentrated on H5N1, a virus of avian origin that mainly affects wild and domestic birds (hens, ducks and turkeys) but can also be transmitted to humans via contact with an infected animal or its remains.

The first human victims were recorded in Hong Kong in 1997, when six people died after contracting the sickness from poultry. The symptoms were similar to those of common flu, but the laboratory analyses confirmed that the cause was an avian virus which had never before affected humans.

Six years later, in December 2003, H5N1 reappeared in Vietnam. Between then and 31 August 2007, bird flu has affected 327 people and killed 199 of them [13].

The biggest fear is that the virus may mutate, allowing it to pass easily from one person to another. If that should happen, there would be a pandemic which, according to WHO estimates, would cause between at least two and seven million deaths [14].

Risk management associated with bird flu is dominated by uncertainty surrounding development of

the virus and the possible health consequences. A new human pandemic is considered probable, but no one really knows if it will be the H5N1 viral stock that will cause it, far less when. Margaret Chan, one of the top officers responsible for the WHO's battle against bird flu admits that our information is still very limited: *"Sometimes you really don't know what you don't know, if that makes sense. When dealing with a new and emerging infection, it is a humbling experience, as I've discovered myself. We should not pretend to know what will happen. Will it be severe or mild? Which age groups will be most affected? We just don't know. [...] I have to tell people what we know, and the truth is we really don't know [15]."*

The need to take urgent decisions in an uncertain situation is one of the underlying characteristics of the risk society. In many cases, the interests at stake and the complexity of the factors involved – think, for example, of the long-term consequences of environmental pollution, the effects of global warming or, indeed, the health threat posed by H5N1 – make it difficult to identify the victims, causes, consequences and possible remedies of risks with any certainty; these elements often defy all attempts to quantify them but, at the same time, they require joint, irreversible measures to be taken [16].

In the same way, in contemporary society, mass communication sets timescales which oblige the risk management institutions to provide information even when incomplete or riddled with uncertainty. The WHO's frankness in telling the public about aspects of the bird flu epidemic of which they are unsure or have no knowledge is a brave choice. From studies of past experiences we know that an honest and open approach, combined with the avowed commitment to use every means available to deal with all possible circumstances – even the most disastrous – strengthens the degree of trust in the organisations that have to manage the risk. This is true even when they admit uncertainty about the information to hand. Despite the criticism of excessive scaremongering, openness and transparency in the WHO's communication activities have enabled the organisation to appear to the mass media and the public as the source of privileged, more authoritative and reliable information about bird flu. Public trust is essential in encouraging people to play an active part and in the ability to meet a possible emergency: *"People are at their best when collectively facing a difficult situation straight-on. Things get much more unstable when people begin to feel 'handled', misled, not levelled with. That's when they are likeliest to panic or go into denial, likeliest to ignore instructions, likeliest to develop paranoid hypotheses [17]."*

AIDS AS AN EXAMPLE OF PUBLIC PARTICIPATION

The AIDS affair is a typical example which illustrates how participation in choices and the formation of a rapport between scientists and the public

(in this case doctors and patients), which can make more of both expert knowledge and so-called "folk wisdom", can be important tools in confronting the uncertainties of what is known on the subject and in making joint decisions which satisfy everyone's interests as far as possible.

In the case of AIDS, it was the American homosexual community that was hardest hit at the outbreak of the disease and their public influence played a decisive role: white, well educated and well-off, experience of the Civil Rights battles fought in the 1960s and '70s meant the US activists had excellent organising abilities; they knew how to mobilise the mass media and get their voices heard [18]. Right from the outset, they proved extremely capable of collecting and distributing every new piece of information on the sickness and its possible cures. They understood that if they were to force doctors and experts to deal with them, then they would have to master the specialist jargon. Always present at international AIDS conferences, most were "amateurs" in the sense that they had no medical qualifications, but they knew more than any doctor about the habits and needs of the AIDS sufferers. They fought a battle and they changed the history of the public health service, obliging the US authorities to reduce the time taken to approve new drugs, finding new, priority routes so that they could receive experimental treatments, forcing the medical community to accept more humane experimental procedures, even at the cost of sacrificing a certain amount of scientific exactitude. During the clinical trials of AZT, the first really effective AIDS drug, they asked the medical world to abandon the so-called "body count" of patients in the control group (who were usually the ones given a placebo) and to stop requiring trial patients to give up other drugs, including those to combat fatal opportunistic infections. Ethical principles which then may have appeared scandalous are now widely accepted in clinical trials. On 20 March 1987, with a therapeutic agreement, AZT was finally approved by the Food and Drug Administration (FDA) after an abbreviated procedure (*i.e.* without undergoing the stage of the experimental trials known as Phase III).

Contrary to appearances, the activist groups, including the famous ACT-UP (AIDS Coalition to Unleash Power), which sometimes promoted noisy protests against American medical institutions (though generally to attract media attention), looked on science as an ally, not an enemy. By renegotiating the doctor/patient relationship, people with HIV claimed an active role in the therapeutic process, asking (and in the end being allowed) to be involved in planning clinical trials, but also to be able to conduct their own research. The FDA recognised value of the latter in 1989 with the approval of the aerosol form of pentamidine, the first drug ever validated on the basis of a community study. In June the same year, the activists' proposals were put on the agenda of the Fifth International AIDS Congress in Montreal (Canada) – a demonstration that includ-

ing the skills of non-experts in the treatment process not only responds to a democratic need, but can also make the process itself much easier [18].

HOW DOES PUBLIC INVOLVEMENT IN SCIENCE AND TECHNOLOGY WORK?

Questions raised by the risk society have sparked off heated discussions and deep thought about the role that we, as citizens, can play in decisions that concern our welfare, the food we want to eat, the medical treatments we want to undergo.

When it comes to facing and managing the conflicting needs of research, financial interests, ethical guidelines and the public view of science, which are themselves contradictory, there is no easy solution at hand.

In the history of infectious diseases such as AIDS and BSE, there is a breakdown in trust between the world of research, politics and all the other social factors involved. It's no accident that the broader relationship between science and society places so much insistence on trust. In 2000, an important document from the British House of Lords entitled *Science and Society* [19] severely criticized the one-way system of distributing and circulating scientific information, stating that it was exactly cases like BSE that showed how great a need there was to introduce a radical change in scientific communication in order to achieve more, and more effective, dialogue with the public.

Even the politicians were increasingly realising that medical and scientific knowledge is not transmitted and does not circulate solely via the traditional channels: formal education, "releases" by scientific institutes, individual scientists or professionals who make it their business to "popularise" science for the general public. Such knowledge is spread, appropriated, discussed, used and traded by different members of society, often indirectly.

The points of contact between these general considerations and governance of the global risks associated with infectious diseases are not always direct and easy to identify. Often these questions are dealt with by disciplines which have traditionally had little to do with each other. Nevertheless, wider discussion of the role non-experts can play in directing the course of developments in scientific and technical research, public reactions and the resulting approach to managing global epidemics do share some common aspects. In both cases, a system of "expert knowledge" comes into contact, and often into conflict, with a system of "lay knowledge". The fact is that, although exchanges between scientists and the public have always existed, the means and forms of interaction and contamination between these systems have multiplied out of all proportion when compared with the past. Rather than the handing down of information from top to bottom, communication is increasingly the area of society in which the value and use of science and even medicine are

negotiated, even in the case of "privileged" information like medical and scientific knowledge.

It may seem obvious, but information that circulates about medicine, science and technology forms part of a complex system of knowledge that creates the public's image of the subject. In a way that cannot be compared to even a few decades ago, this image is influenced by myriads of factors with a vast and varied range of form and content in terms of explicit or implicit communication, produced by public or private institutions, created by fiction, art, publicity, "bottom up" democracy on the part of social movements, NGOs or organised pressure groups.

As regards the images that circulate about possible cures, multi-national corporations such as the biotechnical or pharmaceutical companies hold an important place in the procession of figures who hand out scientific news.

Marcia Angell, former Editor-in-Chief and a staff member for 20 years of the *New England Journal of Medicine*, one of the most-read medical journals in the world, has recently written a searing condemnation of various aspects of drugs manufacturers, especially those in the American market [20].

The data that interest us most are those concerning marketing. It is not easy to obtain the figures for this item of expenditure on the balance sheet but according to a professional association in the sector, the *US Pharmaceutical Research and Manufacturers of America* (PhRMA), in 2001 American pharmaceutical companies spent around \$54 billion on direct consumer publicity, promotional visits to doctors, free samples and advertisements in specialist journals. The figure is larger than the GDP of many of the world's nations. Marcia Angell claims that the spend is in fact much higher, denouncing the fact that a lot of marketing is carried out on the quiet and, especially, that publicity targeted at the consumer is often passed off as health education.

Above and beyond the arguments, even if we accept the PhRMA's statement, and remembering that the cost of getting the message across directly to the public is only one part of the marketing budget, we are confronted with a figure which has no equal in the sums spent on other specific communications activities relating to medicine and research.

Of course, it's not news that some of the latest fictional writing is set against a background of medicine and technology: for example *ER*, *Doctor House*, *Grey's Anatomy*. The plots and language may be different, but all, more or less explicitly, are based broadly or specifically on medicine and techniques practised on the human body.

We could give many more examples, but in this paper we want to focus on how these programmes reveal the existence of countless "bridges" between groups of experts and non-experts, between doctors and patients, researchers and the public; bridges which are continually created, renewed and in a constant state of progression [21].

So, might the field of global health risk management learn something from the experiences and ideas described about the kind of public participation that could help to develop scientific and technical research? As far as we know, there is no straightforward answer to the question and, below, in the hope that we can offer some useful starting points for thought about the matter, we shall show the merits and limits of various theories and practices relating to public participation and democracy when the public meets science and technology.

Much has been written about the role the public can play in directing the course of scientific research, but no really definitive verdict has been reached. In some cases, the form such scientific and technical research is to take, and its objective, are decided, not only within compact, semi-impenetrable social “nuclei” (e.g., policy makers, scientific bodies), but by means of some stormy shifting of those boundaries, on “middle grounds” where experts and non-experts meet, or rather, where experts on a particular subject (e.g., biotechnology) and those who work in another kind of field (e.g., social movements) meet. That’s the type of place which acts as the stage for what Ulrich Beck calls *sub-political hybrids*: politics have not been removed from the picture, but take place in areas that are different from the classic, institutional setup. “Now, the possibilities for organising society are migrating from the political system toward the sub-political system of scientific, technical and economic modernization” [5, p. 186-187]. Decisions on “regulatory” scientific policies, [22] on the way science is organised, assessment of results and the value of research, on social use of scientific information and, sometimes, even on scientific method, are also reached by means of discussions and confrontations which take place in communities extended by “peers” [23] and inhabited by people with different objectives, languages and views of the world.

So it is not surprising that in recent years traditional questions such as the “popularisation” and “transmission” of knowledge, “scientific dumbing-down”, or the “public understanding of science” have gradually been supplemented and replaced by metaphors centred on “two-way” and “interaction”, on “dialogue” (referred to above), on “involvement” or “engagement” and “awareness”. Many scientific institutions and some political arenas have had to acknowledge this new message, especially in Northern Europe.

If the metaphor becomes “listening to each other”, “communic-action” or even goes as far as “bottom up” democracy, there will be no single definable “public”: there are so many different, varied publics that they can no longer be interpreted by the scientific populariser or academic communicator in the field) except via the classic stereotypes (the onlooker amazed by science, the enthusiastic supporter, the cautious, sceptical observer, or the hostile technophobe) [24].

Many, if only from the point of view of the language they choose to use, are beginning to treat the public as a collection of different, active people who not only “receive” information, but have the ability to, and do, use it to take important decisions: those involved in the development of techno-science can bear this out.

In some cases, such public participation takes the classic forms typical of every country where the population decides on significant matters. In Italy, for example, popular consultation on environmental, scientific, technical and ethical matters often takes the form of a referendum: we need only think of those on abortion, hunting, nuclear power or, more recently, assisted reproduction technologies.

In other cases, public participation assumes new and specific forms, such as “consensus conferences”. They originated in the United States (in the National Institutes of Health) as a means of bringing together specialists who would assess the degree of safety and effectiveness of certain medical techniques. Then, in the 1990s, in Denmark, consensus conferences became transformed into meetings for exchanges and discussions between specialists and “ordinary citizens”; these meetings became the basis for the citizens to provide assessments and detailed reports (intended for politicians) of the discussions on issues considered critical [25]. Consensus conferences soon spread like an oil slick, especially in countries where dialogue was beginning to be seen as a more important issue than the question of overcoming the “deficit”.

In the 1990s, such experiments in deliberative democracy were applied in various formats and to distinct aspects of managing science or technology. Small groups of citizens (usually fewer than 20 people) held discussions with experts before expressing a consensus and providing the government with recommendations on the key questions they judged to be critical: the Danes formulated their own assessments on the irradiation of foodstuffs, sequencing the human genome, information technology, cloned animals and infertility. The British discussed vegetable biotechnology and what to do with radioactive waste. Koreans, Japanese, Americans and Canadians carried out many similar experiments.

Apart from a few enthusiastic commentators who see consensus conferences as the practical implementation of new forms of deliberative social participation for the governance of science and technology, it appears obvious that such explicit trends in “bottom up” democracy are, for the time-being, marginal, restricted to a few countries and associated with specific subjects or specific moments of crisis when an urgent need arises to construct (or focus on) social dialogue before and during policy formulation. In some cases, the expedients intended to respond to the new buzzwords (“extended democracy” and “participative”, for example), appear to be linguistic devices which are

not met (and perhaps could not be met) by a corresponding and authentic *empowerment*. Industry or government may have an interest in resolving or controlling social conflict by playing tricks with an extended democracy which, in practice, is governed only in the slightest degree by different groups from those that dominate the global market. In other words, it is impossible to establish whether public participation is an ephemeral phenomenon that will vanish as quickly as it came, or whether it represents a profound change in the decision-making process that concerns scientific and technical matters [26]. Furthermore, we should remember that the problem of public participation has a long tradition in the history of democracy, even if the thinking on the “democratisation” of science is much more recent.

In the recent history of scientific communication, this is not the first time there has been discussion and consideration of issues and proposals which have already been faced and, in some cases well and truly dealt with, in other areas. Even in the matter of public participation, there is a risk of reinventing the wheel.

Nevertheless, as we see it, consensus conferences, referenda, citizens’ panels are extremely important phenomena. First of all, because they represent the visible tip of the iceberg that consists of the innumerable channels that communicate, appropriate, and socially reconstruct science. Media men and politicians, entrepreneurs and NGOs, local organisations and scientists, doctors, judges, lawyers, workmen all share and exchange scientific information; sometimes they construct new information, at others they negotiate the significance of such information or the values it should be accorded and, in this way, in the end, they all become active participants in controlling science and technology

– though the influence and impact of each participant may be different. The variety of formats, even the guise, in which such awareness or participation are visible is an indication of a world which, perhaps, is changing. Furthermore, other phenomena, sometimes unofficial or non-establishment, constitute a strong, concrete (even if indirect) influence on the techno-scientific world. These phenomena are not connected solely with moments of crisis: on the contrary, they are natural, functional elements which enable science to form part of our culture, and society appropriates science and technology, moulding them to itself. What consumers decide they don’t want to buy has a powerful influence on what industry decides to produce and, therefore, on what the multinationals (*e.g.*, the drugs industry) decide to research and develop. The influence of what citizens decide is harmful or beneficial affects not only the private, but also the public research world; not only applied but also “basic” research; not only strategic but, sometimes, even methodological or epistemological choices.

But can science really be decided on a collective basis? Can the public really direct its course? Isn’t there a risk of an “audience dominated” policy, or a sort of techno-scientific populism?

Obviously, the solution is not simple. Certainly, however, the answer to these questions will not be reached through diminished, restricted dialogue, which in any case is now impossible, but by the strengthening of social debate. Whatever the democratic trends in social control of science, they will only be effective if communication is effective.

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