



## Health

FRÉDÉRIC SGARD, PROJECT ADMINISTRATOR, GLOBAL SCIENCE FORUM, OECD, RAPPORTEUR

### Session 1: The Social Challenges of Stem Cell Research

Chair:  
Claude Huriot, Director, Institut Curie (France)

Speakers:

- Marina Cavazzana-Calvo, Head of the Department of Biotherapy, Hôpital Necker (France)

*"Stem Cells - from Basic Research to Applications: the Society Expectations"*

- Austin Smith, Director, Wellcome Trust Centre for Stem Cell Research, University of Cambridge (Great Britain)

*"Pluripotent Stem Cells from Embryos and Adults"*

Discussant:

- Didier Sicard, Professor, Université René Descartes, former President, Comité consultatif national d'éthique (France)

### Session 2: Safety and Health Crises

Chair:  
Didier Tabuteau, Director, Chaire Santé, Sciences-Po (France)

Speakers:

- Paul Dorfman, Senior Research Fellow at the NHS Centre for Involvement, University of Warwick (Great Britain)

*"Radiation risk, rationality and citizen involvement"*

- Michel Setbon, Research Director, CNRS, Head of the Centre interdisciplinaire sur le risque et sa régulation, Ecole des hautes études en santé publique (France)

*"Risks and crises in the Nuclear Industry: The La Hague model"*

### **Session 3: The User in the Health System**

Chair:

Gilles Duhamel, National Inspector for Social Affairs (France)

Speakers:

- Johan Hjertqvist, President, Health Consumer Powerhouse (Sweden)

*"Europe of the Healthcare Consumer"*

- Christian Saout, President, Collectif inter-associatif sur la santé (France)

Health is a very sensitive area in so far as it affects everybody intimately. Everybody has been, is, or will be faced with health issues. Everybody knows somebody close to them who is seriously or even fatally ill. Society therefore has huge expectations in matters of health and hence of medical research.

Health and associated research are also characterized by two aspects – the individual and the collective. They are individual in so far as medical research impinges on our own person, involves trials on human beings and, because the patient has by definition a part to play in the treatment administered and because they entail a need for dialogue between researchers, doctors and citizens. They are collective in so far as many diseases or health risks have a general dimension, involving actions or responses from public authorities, which in turn also require a relationship with the general public.

This workshop, which is divided into three sessions, enabled us to define a certain number of specific features peculiar to health and medical research and to the dialogue which needs to be established between the different parties involved.

#### REPORT ON “THE SOCIAL CHALLENGES OF STEM CELL RESEARCH”

This session illustrated an initial element specific to medical research, namely that it is a scientific area in which knowledge is developing very fast, so that very few real scientific certainties exist in the most cutting-edge fields. The issue therefore arises of the appropriation of transient scientific truths by society. As was highlighted by the chair of the session, Professor Claude Huriot, there exists simultaneously a very strong societal demand on the part of the citizen, who has become a consumer in matters medical, a knowledgeable consumer of knowledge and innovation. This places great pressure on researchers for results, which can lead to a mismatch between expectations and the real applications of these discoveries, as well as to unsatisfactory research conditions (i.e. difficulties obtaining funding for research which is not justified by therapeutic ends).

The example of stem cell use was very representative of the issues as a whole (issues of ethical use, medical safety, financial exploitation, etc.) in which the different actors in the dialogue are involved. In ethical terms in particular, Professor Sicard, former President of the National Consultative Committee on Ethics emphasized in discussions the utopia of ethical regulation of innovations, whilst warning of the risk of the orchestration of science by ends other than knowledge.

Presentations by the two scientific speakers, Dr Marina Cavazzana-Calvo and Professor Austin Smith, cast light on the linguistic gap existing between scientists and members of the public on such cutting-edge topics. However, dialogue is necessary in spite of these difficulties because these scientific discoveries can lead citizens and society to ask themselves more general, ethical, economic, social or philosophical questions. The scientific community, therefore, has a responsibility to initiate this dialogue, as was done successfully in the United Kingdom, for example, on the issue of stem cells, but there is also a need to define a common language which is not exclusively scientific, possibly requiring intermediaries or mediators.

#### REPORT ON “SAFETY AND HEALTH CRISES”

The second session highlighted the importance of structured dialogue when faced with public perception of threat. Whether the threat be from infection or, as in the instances presented in the workshop, nuclear power, it can lead to health crises whose treatment is made more complex by several factors.

The first of these factors is the difficulty experienced by the public in understanding the concepts of statistical risk and uncertainty. A health risk can be calculated in the

majority of cases, but there is often a series of biological, epidemiological or other elements which remains uncertain. The difficulty for public authorities lies in transposing these uncertainties into certainties in terms of regulations for prevention or cure. These uncertainties and the variable perception of risk on the part of the public generate their own interpretation of scientific data and conclusions. In the event of a health crisis, there is a juxtaposition between political certainties and social uncertainty which reinforces the need for open, structured dialogue.

A second characteristic feature of safety in health is its collective dimension, which requires a response in the form of collective dialogue. Yet we observe in health matters that social debate often, or even only, moves forward when there is a crisis. In tandem with the hopes raised by medical research which create the social pressure described above, health is also a cause for anxiety and fear. In a sense, crises provide as many opportunities as they do risks for science.

The examples given by speakers in the course of the session demonstrate the gap which often exists in society between perception and reality of health risks (both in a positive and in a negative sense) and the need for open debate, since failure to do this costs society dear. One of the essential elements of this debate is for the different parties to accept that they do not possess “the *de facto* truth”, to avoid absolute cer-

tainties and to recognize the possibility of being wrong. One interesting lesson to be learned from health crises, apart from the importance of initiating dialogue early, is that the simple fact of engaging in dialogue in a spirit of openness can reduce the crisis at a social level, even if no final consensus is achieved.

Christian Saout described another approach, which consisted of taking part in dialogue by becoming part of the system itself. A slow rise in patient participation in the health system can indeed be observed, but more often than not this still only takes place during crises in a reactive rather than a preventive manner. Health service user bodies have only recently obtained legal status in France (2002) and still encounter many barriers erected both by health professionals and the authorities. Different States undoubtedly need more constructive dialogue with society if they are to respond to the enormous challenges of the ageing population, chronic ill-health or lack of resources.

This essential dialogue between health system users, professionals and the authorities therefore raises several unknown factors: for the dialogue to be effective is the best place for the patient inside or outside the system? How can the risk of health service regulators or producers orchestrating participants be avoided? How can we make available or use the huge amount of information stemming from the medical research which is developing all the time?

In more general terms, we can see that dialogue on health issues between scientists, experts, governments, administrative authorities and members of the general public is still suffering from serious limitations. Although this is an area in which public demand for information and involvement is

80

**REPORT ON “THE HEALTH SYSTEM USER”**

Themes  
and  
Questions for  
Dialogue

As was mentioned by Gilles Duhamel in his introduction, users are increasingly well-informed about their diseases and treatments available. They therefore want to be involved in the decisions made concerning them and to be a stakeholder in a system which is still essentially controlled by health professionals and public authorities.

For Johan Hjertqvist, there is still a significant gap between experts on the one hand and patients on the other, in spite of the introduction of patients' rights in many European countries. Yet the patient is requesting information and knowledge in what is increasingly developing into a health service marketplace. It is therefore necessary to build a bridge between these two worlds, as is being attempted by a number of associations and organizations. By carrying out health service performance measurement from outside the system, these organizations are a positive force for improvement.

very high, discussions are often limited to experts. Unlike other areas such as the environment or planning, for example, public debate on health is still in its infancy and it only makes sporadic progress when there is a serious crisis.

What health requires is the growth of mechanisms for open, transparent debate, promoting greater involvement on the part of society in this crucial area. The rapid growth

of new technologies which raise social issues (genetic testing, stem cell research, etc.), demographic growth and the appearance of new diseases are all subjects on which society cannot avoid initiating more open dialogue. It is time to put the necessary mechanisms in place to establish this dialogue in order to avoid further crises of confidence which will be detrimental to all concerned.