Project description

Science in public:
Drawing lessons from the gene therapy debate of the 1990s

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The issue of good scientific communication practices constitutes the core of this project, aimed at improving the foundations for ethical reflections and deliberations on the role of science and the conduct of scientists in public life: the public relations of science. What kinds of problems are scientists confronted with in this context? And how may such problems be dealt with in ways that accord with scientific traditions for open, critical and sceptical discussion? (Merton 1968: 591-615)

The public relations of science has received only scant attention in recent attempts to adjust the norms and guidelines of research ethics to those changes in the conditions for scientific activity that have marked the most recent decades (Committee on Science … 2009; Macrina 2005; Shamoo & Resnik 2009; Udvalgene vedrørende Videnskabelig Uredelighed 2009). Such attempts – concerned, like the present project, primarily, but not exclusively, with the biological and technical sciences – have generally acknowledged that scientists may have vested interests, not the least of a financial nature (Braxton 1999; Resnik 1999). The increasing dependence of scientists on external funding and the growing commercialisation of science have been acknowledged as ethical challenges. Consequently, demands that possible conflicts of interest be declared are becoming standard in, for instance, submissions to academic journals and applications for research funding.

Despite the growing societal significance both of science and of media, however, the afore-mentioned developments have not been accompanied by thoroughgoing attempts to (re)think the ethics of science communication. As a rule, two traditional maxims are left to govern this particular field of activity: Firstly, scientists should avoid going public until after publication in a peer reviewed journal. Secondly, they should take care to maintain the reputation of science.

As a result, individual scientists risk being left on their own to face such problems and dilemmas as: When is it acceptable to express and, thereby, inspire hope about possible outcomes of research projects? Which qualifications and aspects of uncertainty should be emphasised? And which possible conflicts of interest? What is the difference between public relations and PR? And what should be considered a proper response when research funding comes with confidentiality demands? What kinds of findings should be considered to be so important that they must be accessible to all?

There is evidence that questions such as these currently cause concern, for instance among bioscientists (Meyer 2005; Folker et al. 2009). In order for such concerns to be converted into something more fertile than mere frustration, however, a thorough knowledge of actual, apposite examples is needed. Such knowledge, in turn, may then form the basis for a measure of collective self-reflection and -critique. Against that background, the case of this project has been chosen: The public debate on gene therapy as it unfolded 1992 and 1995 in Danish, German and British newspapers, reports from parliamentary committees and other documents aimed at the public at large.

The gene therapy debate: a case study

In the early 1990s, gene therapy was pivotal to public discussions about technology. Expectations were great. Optimistic visions were presented about ground-breaking new treatments, encompassing a whole range of cancers and various mono-genetic disorders. At the same time, pessimistic visions were presented regarding potential treatments of so-called normal traits as diseases, and about the

possible manipulation of germ cells and, thereby, the introduction of hereditary treatments. Conscientious and enthusiastic discussions focused on the issue of governance in this new and important field of activity, and on what should be left to market forces (Committee on the Ethics of Gene Therapy 1992; Meyer 1995; Moore 1993; Århus Amt et al. 1995). Actual development, however, has not lived up to these visions.

Currently, the gene therapy debate tends to appear only in passing remarks as an example of how a debate may be marked by exorbitant expectations (Nielsen 2007a; b), but what, in fact, was the content of those exorbitant expectations? By whom were they harboured and entertained? Were sceptical questions raised at all?

Lessons about the public relations of science and the conduct of scientists in public life may be drawn from the gene therapy debate. The purpose of the present project is to actually identify such lessons, using an international perspective and focusing on the relations between visions, realism and scepticism in public discussions about science and technology.

Society, and science as a societal institution, need specific knowledge that can serve as a basis for principled and practical exchanges about how an open, critical and sceptical public debate on science-related issues may be maintained. To participate in that kind of debate is demanding to all and represents an ethical challenge in particular to the scientific community.

A neglected aspect of research ethics

The current economic conditions for scientific activity carry incitements to conduct which may harm cooperation between scientists and is contrary to traditional, scientific values. That is the background of the revisions of norms and guidelines about research ethics mentioned above. The incitements appear to be present also with respect to the public relations of science: Demands for visibility come with incitements to over-sell research projects and play down uncertainties and possible conflicts of interest (Meyer 2006; Nowotny et al. 2001: 38). On the other hand, research funding may come with confidentiality demands which may result in important information being withheld from the public.

Nowadays science is, as a rule, science no longer considered an outsider to society. Generally speaking, there has been a break with the traditional view of science as "a self-validating enterprise which was in society, but not of it" (Merton 1968: 605). It is now widely recognised that social relations form part, not only of society as an outer world, but also of the world of science. In connection with this development, the outcome which society at large may expect from science has been redefined, from 'reliable knowledge' (Ziman 1978) to 'socially robust knowledge' (Gibbons 1999). Discussions on research ethics tend, however, only to deal with such aspects of conduct that are internal to the scientific world. Curiously, the old assumption of a radical science-society divide seems to have been maintained in the mainstream understanding of the relations between science on the one hand and the media and public life at large on the other. Research ethics and communication ethics appear disconnected and, as such, are dealt with as separate entities, as seen for instance in EU research programmes (European Commission 2007a; b). The ethics of science communication seem almost to be taken for granted.

Science as a societal institution: an ethical perspective

As a rule, science and technology studies are concerned with science as a social phenomenon, thereby emphasising one of several valid perspectives on society. The present project will be using a practical, ethical perspective on science as a societal institution. Thus, it is concerned with aspects that may serve to facilitate reflection on future actions, on obligations and responsibilities, and on the conditions for the fulfilment of such obligations. Rather than focusing on power relations or on relations between 'elites' and 'masses', the project will enquire into widespread routines, norms and

assumptions in order to open them up to reflection and possible revision. As a troubled attitude to politics forms part of the history of modern science (Nowotny et al. 2001: 63; Shapin & Shaffer 1985: 76), this applies not the least to assumptions about the relationship between science and politics.

According to the theoretical framework of the project, the recognition of science as a societal institution implies more than the acknowledgement that science is not immune to social reality. It also implies an acknowledgement that science forms part of the political and democratic reality which is conditioned by unpredictability, diversity and disagreement, and by the fact that collective decisions must be made under precisely those conditions (Crick 2005; Meyer & Sandøe 2006; Meyer & Lund 2009). Science and politics are not regarded as opposites, but as basically different activities. The notion of good scientific public relations or communication practices is taken to signify norms and routines that facilitate the integration of scientific and technical knowledge into a societal context of plural concerns and arguments (Gadamer 1975: 531), and demands that all participants continuously and critically deal with the task of maintaining their own trustworthiness (Meijboom 2008) and truthfulness (Williams 1993).

It has been argued that the ethos of science, as codified by Robert K. Merton in 1942 (Merton 1968), has been rendered obsolete by the current conditions for scientific enquiry (Nowotny et al. 2001: 240-41). This project, however, takes as its point of departure that current challenges actually serve to emphasise the importance of maintaining traditional, scientific values (Barnett 2004: 83), and that the norms of open, critical and sceptical discussions remain crucial also in respect to the ethics of science communication. Only, the assumption of a radical science-society divide that Merton took for granted is not compatible with the obligations of science as a societal institution.

Crucial assumptions about the public and public life

The project's thesis is that widespread assumptions about a radical divide between science, on the one hand, and public and political life on the other, have a negative impact on public debates about science-related issues, and on considerations about science communication. Such assumptions – which could easily become self-fulfilling – have for instance been stated succinctly by the climate scientist Stephen Schneider, While describing internal scientific discussions as being marked by a commitment to truth, by critical exchanges and honesty, he linked public and political discussion to attempts to achieve broad-based support by means of dramatisation and simplification and by downplaying aspects of doubt and uncertainty (Schneider 1996). To financially hard-pressed scientists not the least, such assumptions could serve to legitimise problematic communication practices.

The thesis will manifest itself in the analyses of the project in terms of a particularly keen interest in the phenomena of dramatisation and emotional appeal. These phenomena, in turn, can be linked to the idea of the lay person – a character that can be defined only in negative terms as not having knowledge, as being an outsider as opposed to an insider (Ordbog over det danske sprog 1966). It will be a criterion for the selection of textual material to be analysed during the project (see the following section) that it targets so-called lay persons rather than colleagues from science. And it will be a theoretical aim of the project that such assumptions about a lay audience that are expressed in the textual material, be subjected to a critical examination.

Modern science inherited and secularised the notion of the lay person from the medieval church, and this notion seems to have been fused gradually with ideas about the public as a mass audience (Arendt 1958; Enzensberger 1964), and about consumers. In this variation, the notion may currently be encountered in the shape of references to 'ordinary people' or 'average citizens'. Expectations about the public as audience are likely to affect, both substantially and with respect to form, how that public is addressed. A critical examination of widespread ideas about the public,

therefore, is, at the same time, of theoretical, practical and ethical significance. Moreover, it is of relevance also to the practice of science journalism and its predominant convention of science transmission, relating precisely to the transportation of scientific knowledge to the public, conceived as an audience of lay persons (Friedman et al. 1986; 1999; Hornmoen et al. 2006).

Method

It is the initial empirical aim of the project (Eneroth 1984) to shed light on the expectations that marked the gene therapy debate: What kinds of expectations were expressed by, respectively, scientists from the field of gene therapy, journalists, ethicists, politicians, and representatives of patients' organisations and the pharmaceutical industry? How were aspects of uncertainty and potential conflicts of interest presented? What reservations were made and by whom, and how did such reservations influence the presentation of future gene therapy as a whole? The debate was not peculiar to Denmark, but was, rather, an international phenomenon. Were the debates in Denmark, Germany and the UK significantly different as regards these aspects?

The empirical nucleus will be composed of the same kind of material from each of the three countries: text units from newspapers from 1992 to 1995 – a classical broadsheet and a tabloid, selected with a view to comparability – and a parliamentary report discussing gene therapy from the end of the period. The selection of text units from the media will be adjusted (by searching for text units from whole years or from randomly chosen months of each year) to achieve a goal of obtaining between 200 and 250 text units per country. In this manner, a close reading and comparison of the textual materials will be facilitated, and initial content analyses will be allowed to impact decisions about further procedures (Gadamer 1975). As a result, the collection of supplementary material – for instance press releases from agents such as patients' organisations, pharmaceutical companies and scientific institutions – will be informed by the initial close reading of newspaper text units and parliamentary reports.

After having distilled the expectations from the gene therapy debates, these expectations will be compared – by means of literature studies and interviews with gene therapy specialists – to the actual development that has taken place in this area of science and technology.

We are currently living in the future of these past debates: A time frame of 15-20 years was commonly used for the purpose of emphasising that the realisation of visions would (only) take place in the future. It makes good sense, therefore, to compare the expectations of these past debates with the actual, current state of affairs. At the same time, the time lag decreases the risk of the enquiry inciting unproductive conflicts and mutual accusations among groups of agents. This is also likely to be prevented by the fact that the enquiry is concerned not with finding somebody to blame, but rather with the identification of shared problems and challenges, and the facilitation of reflection and exchanges on how to face up to such challenges. To these purposes, the project combines two different activities: empirical investigation, and a contribution to the development of normative theory and thought.

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