Societal dialogue needs more than public engagement

SSS Science & Society Series on Convergence Research

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The term 'dialogue' has become an important part of 'science and society' discourse during the past decade. As such, statements like the following have become integral to reports and activities at the interface of science and society: "The acquisition of a basic grounding in science and technology by the European public and a regular flow of information to the public from experts are not in themselves enough to enable people to form an opinion. A true dialogue must therefore be instituted between science and society" (European Commission, 2002). 'Dialogue' is now a commonly used term in policy papers and social science articles to describe 'multi-way' communication between science as an academic activity and society as the larger context of science and as its potential beneficiary. Public dialogue is supposed to contribute to scientific and technological developments that take into account societal concerns, values, priorities and institutions—which social scientists have termed 'socially robust knowledge' (Nowotny *et al.*, 2001). This requires societal actors to assess the pros and cons of technological and scientific developments, as well as scientific experts who are able to connect the laboratory to the world outside.

Dialogue is about 'publics' and experts, who learn both from and with one another about where scientific research can, will and should go. However, dialogue is often presented as public engagement with an emphasis on the involvement of citizens giving input for policy or decision making (Davies *et al.*, 2008). As initiators and organizers of online discussions with publics and

experts on genomics, we have learned that public engagement is just one of the challenges of generating a dialogue—and not even the most difficult one. Another requirement is to engage experts. Ultimately, generating a dialogue, in practice, is about both publics and experts articulating the object of discussion.

As part of a pilot project called 'The DNA-Dialogues', we organized online discussions in collaboration with the editors of a popular magazine in The Netherlands, and specifically invited experts in genomics or science policy to take part. In this article, we describe the interactions between experts and the public during two online discussions that took place on the discussion board of *Ouders Online* (*Parents Online*), a popular Dutch online magazine about parenting (www.ouders.nl).

In the spring of 2007, Maud Radstake started a discussion on the *Ouders Online* website about whether blood from standard neonatal screening—taken by a heel prick from newborn babies—should be stored for longer than the current period of five years. The topic was initially raised in an invitation-only expert workshop—that one of the authors attended—in which the legal and ethical possibilities of extending the storage period were explored, and the current restrictions on the scientific use of data obtained through the neonatal screening programme were addressed. Dutch scientists and policy makers, regretful about the destruction of what they consider to be valid material for future genomics research and epidemiological analysis, had organized the workshop. Although the

participants largely agreed on the urgency of the issue, they anticipated resistance from parents and interest groups, and discussed ways to address the concerns that were likely to be raised. As such, a Centre for Society and Genomics' (CSG; Nijmegen, The Netherlands) staff member proposed to organize an online discussion on the topic, and *Ouders Online* cordially accepted.

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The dialogue started with a short article introducing the topic for *Ouders Online* (Radstake, 2007). It discussed the scientific arguments for longer storage and the required regulatory changes in regard to informed consent or opting out. The article also mentioned privacy concerns, and briefly discussed the idea that providing blood for research fosters solidarity between individuals and generations. Generally, these were issues that the scientists considered to have relevance for the public and for parents in particular.

The article invited readers to post their reactions to the discussion board. The opening message posted by the editors of *Ouders Online* asked: "What should happen with the heel prick blood?" The scientists and policy makers who had participated in the workshop were also

invited to take part in the discussion. We explained that they were not simply supposed to provide information, but rather to engage in an exchange of views and ideas with the other participants: we used the word dialogue to describe this objective. Of the five experts who originally expressed interest in participating, only one eventually did. Like the majority of participants at the original workshop, this professor in the field of public health considered privacy and the need for informed consent to be the most important societal issues related to blood storage and use.

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Among the participants in the discussion were 13 mothers, the professor, a member of a non-governmental organization known for its critical stance towards human genetics research and biobanking—who had been invited by the CSG—and the CSG staff member who had attended the workshop and organized the discussion. The whole discussion contained 45 messages and took almost two weeks.

The article and the opening message evoked diverse reactions from the participating parents: some did not see any problem, others emphasized the importance of complete and timely information, whereas others fiercely opposed the whole endeavour because they feared their privacy—or that of their children—would be violated, particularly if commercial firms, insurance companies or certain government agencies obtained the data.

Although the parents appreciated the information provided by the scientist, some of them requested more than scientific information and urged her to address the issues that they considered important, such as the possibility of the misuse of the stored blood samples. One parent in particular rejected the framing of the issues by the expert in terms of population benefits and the importance of privacy and informed consent. She stated that: “I have the impression that you [the scientist] are somehow stuck in your own frame. For the benefit of a proper dialogue, I would very much like to open your frame to another perspective.”

This parent, who argued that the blood samples should be anonymized immediately and destroyed after five years, was not greatly concerned with the protection of data by scientists, but was suspicious of commercial and political interests obtaining the samples or data. As such, she asked the scientist to take responsibility for addressing such matters. However, she not only challenged the scientist, but also called the discussion organizers to account, asking: “Why did you think involving parents in this discussion could mean anything?”

As organizers, we responded to her questions by explaining our objectives: that our intention was neither to force the participants to accept the needs and goals of genomics research, nor to promise that the opinions expressed would bring about change, but rather “to inform both researchers and (potentially) involved citizens about what is going on, and allow them to form an opinion about it and let it be heard [by the other parties].” We had not anticipated that we would become so involved in the discussion—we originally thought of ourselves as intermediaries between the scientists and parents; however, we soon realised that we could not maintain a neutral position.

Although the argument put forward by the critical parent was vociferous, the scientist neither withdrew from the discussion nor fully addressed the concerns raised. She did not deny the importance of the issues that this parent and some others raised, yet she could not relate these to her own professional agenda or responsibilities. In personal communication after the discussion, she said that she had appreciated the discussion, because it presented the worries of the public, which should be taken into account in the design of public education and communication. This scientist regarded the discussion as a ‘diagnostic instrument’ to discover public misconceptions about the storage of blood samples. Her own role, as she saw it, was to provide information to eliminate such misconceptions.

These perceived misconceptions seemed to be the main reason why the other scientists did not join the discussion, although they had initially expressed an interest. One of them told us that he had been put off by the aggression, ignorance and emotions that were displayed

in some of the messages. This scientist had expected that parents would be concerned about things that he and his colleagues felt worthwhile and relevant, yet what he read was a discussion on rather different issues. In the same e-mail, he stated that he had expected and preferred to talk to “young or prospective parents with serious questions”, and that he did not see any value in exchanging views with a public that failed to address relevant questions and issues.

This example demonstrates the difficulties faced when organizing public dialogue to contribute to the socially robust development of science and technology. We learned that engaging scientific experts requires at least as much attention and effort as engaging citizens. For both, participation cannot be reduced to an ‘information’ role, but also requires a critical and open attitude. Regular participants of the *Ouders Online* discussion board are used to being challenged and critically approached by their peers; scientists, however, tend to fall back on their professional expertise in an environment that is largely unfamiliar to them, and imagine a public that values their expertise, often assuming that those who disagree are ‘ignorant’.

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In the spring of 2008, Ninne Jeucken initiated another discussion on *Ouders Online* to discuss possible diagnostic tests for autism in young children. Recent research in psychology has provided new diagnostic tools for autism (Dietz *et al*, 2006; Swinkels *et al*, 2006), and the international Autism Genome Project (AGP; National Institutes of Health, Bethesda, MA, USA) has identified several genes that are involved in the development of pathophysiology associated with autism (AGP Consortium, 2007). These scientific developments could affect current diagnostic tests or give rise to new ones; indeed, a pilot project in Dutch child-health centres is already implementing a new behavioural test. Given the recent developments in the AGP, a combination of behavioural and genetic testing might become a feature of future autism diagnosis. In an article on

the website, we introduced these developments and asked parents: “How do we want to handle future possibilities of scientific research? Are scientists addressing the questions that parents consider to be important? And which questions do parents actually consider to be important?” (Jeucken & Radstake, 2008).

We invited several professionals and experts to participate in the discussion, but only two scientists—one involved in the development of the behavioural test and one involved in the AGP—eventually participated. The issue of autism diagnosis engaged many more parents than the discussion about storing neonatal blood samples. In all, the discussion comprised 300 messages posted over a period of five weeks.

The child psychiatrist, who is involved in the AGP, posted 10 messages during the discussion, in which he emphasized the importance of caring for children with autism and called for a discussion focused around societal responsibility. When parents mainly exchanged their personal experiences and views, however, he did not interfere. Several parents interpreted this as a sign of indifference from the experts towards a context outside the research laboratory: “I get the impression that (some of)

the experts believe that the treatment—that is, doing something with the diagnosis—will be there, that it will be fine [...] and that it is not really their responsibility.”

In common with the first discussion, some parents questioned the experts and the discussion organizer about the framing of the topic. They objected to a focus on an early diagnostic test for autism while good care and education for autistic children is still lacking. This caused tensions between the parents and experts. The psychologist who was involved in the development of the behavioural test explicitly acknowledged the problem of finding the right care and education for an autistic child, and additionally stated that she was “curious to hear parents’ experiences”. However, some of the parents found such a response troubling: “Your remark actually scares me a bit. It sounds as if normal life in daily practice is really far from the world of research. It is impossible to inform

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you and the experts who read this in this thread.” Despite her initial enthusiasm, the psychologist soon withdrew from the discussion. It should be noted, however, that other parents empathized with the experts and understood their withdrawal.

In both discussions—on autism and on blood samples—parents wanted to broaden the scope of the conversation to include their own concerns and priorities, while the experts found it difficult to engage with ‘off-topic’ contributions. To many parents, however, it was not evident what the actual topic was and why it should be the focus of the discussion; in fact, the choice of focus was often what they wanted to discuss with the experts. The scientists, however, felt uncomfortable talking about issues beyond their expertise and their perceived responsibility.

The set-up of The DNA-Dialogues evoked particular roles, positions and responsibilities for the public, experts and organizers that are not necessarily self-evident. First, the online discussions in The DNA-Dialogues reflected a notion of public that is different from the one commonly used in public-engagement activities. In order to ‘attract’ people to

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discuss genomics-related issues, we chose those places where people already gather for debate about topics such as health, life-style or privacy. It was our task to connect these issues to genomics. Our approach therefore differed from public engagement activities, such as citizen juries or consensus conferences, where the participating public are selected from a pool of citizens who do not have an obvious or *a priori* interest or stake in the topic (Irwin, 2006; Lezaun & Soneryd, 2007).

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On the *Ouders Online* web forum, we tried to involve people who considered the issues that we identified as potentially relevant for themselves or for society: "those affected by the indirect consequences of transactions to such an extent that it is deemed necessary to have those consequences systematically cared for" (Dewey, 1927). Although the articles invited people to participate, we did not actually engage the public; rather, the issue did (Marres, 2007). The issue was not the particular 'techno-scientific' development in itself, but the uncertainties about knowledge and norms evoked by that development in a particular societal context (Hisschemoller & Hoppe, 1996; Wynne, 2007).

Second, the role of the experts caused tensions in both discussions. Although the use of existing online discussion boards 'solved' the question of how to get the public interested, we had created a new problem: how to engage experts. Indeed, it was not easy to keep them on board. Parents called them to account on issues that the experts had largely considered to be beyond their

expertise, responsibility or control. In the first discussion, the scientist was drilled about possible commercial or political misuse of stored blood. In the second, the experts were criticized for failing to consider how to care for the children who they would help to diagnose as autistic.

In both discussions, the experts largely remained on the 'sending end' of the interaction. They mainly responded to questions related to their expertise, and found it difficult to talk about 'off-topic' issues. From our observations and from interviews with the experts after the discussions, we learned that they struggled with appeals to rethink their own attitudes about issues that parents considered to be crucial. They had anticipated that the parents would represent the future beneficiaries of their research results—provided that the availability of scientific knowledge and technology would be accompanied by correct, accessible, timely and considerate information. In their view, an online discussion was a diagnostic instrument with which to learn about the views, opinions and worries of this particular public. What actually happened, however, was that the discussion did not so much inform them about public opinion but involved them in its formation.

Third, we were unable to remain neutral mediators. By selecting the medium and writing the opening article, and by inviting and informing the experts, we had framed the original topic. Our framing work continued when we responded to questions about the purpose of the discussion or summarized arguments to regain focus. Some parents complained that we framed the discussion too narrowly, whereas we felt that some focus was needed to keep the experts on board. We were soon urged to play an active role in the discussions or to express our opinions. Whereas parents considered us to act as advocates of the scientists, the experts expected us to act as translators between

them and the public. Our job became one of balancing public and expert engagement by means of opening up the discussion, rather than closing it down in one direction or another (Stirling, 2008).

Despite the various tensions that we experienced during the pilot, we have decided to continue The DNA-Dialogues. In fact, we have decided to do so because of the very tensions that we experienced. Our active involvement in the organization of online discussions provided us with excellent opportunities to learn about the factors that stimulate or impede dialogue between publics and experts. The pilot not only produced rich data for analysis, but also created room for experimentation. We hope that our experiences can inform publics, experts and organizers of public dialogue about how to play a more constructive role in further explorations of public dialogue focused on genomics. Such dialogue is not merely about engaging publics and experts, but ultimately concerns the creation of spaces where publics and experts together can articulate the fundamental issues at stake in genomics science and technology, and where those issues need to be addressed.

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