BioSocieties (2006), **1**, 91–95 © London School of Economics and Political Science 2006
doi:10.1017/S1745855205050143

Between Dreams and Reality: The Dutch Approach to Genomics and Society

Marli Huijer
University of Groningen, Faculty of Philosophy, Oude Boteringestraat, 52 9712 GL Groningen, The Netherlands
E-mail: Marli.Huijer@rug.nl

Abstract
The Dutch approach to genomics and society is taken as an example to show that the dream of achieving a symmetrical dialogue between social and bioscientists is not easily realized. Dutch social science and genomics experts aspired to create a bottom-up network for society and genomics that would enable social scientists to bring their own expertise and views into the dialogue with bioscientists. However, in the final stage of founding the network, this aspiration was nipped in the bud. As a result, the genomics and society research agenda has become primarily governed by the desire to adequately implement genomics in society.

Keywords Biosciences, Genomics, Interaction, Peer review, Social sciences, The Netherlands

Interaction, dialogue and interdisciplinary cooperation are key aspects of present-day relations between social scientists and bioscientists. They suggest a symmetry between the social and biosciences, each equally valuing the other's expertise and controlling the contents of the dialogue. A laudable dream, but how to make it come true?

Let me take the Dutch approach to genomics and society as an example in order to examine how social and bioscientists succeed or fail in reaching a symmetrical dialogue. In addition to the peer-reviewed programme on the societal component of genomics research, initiated by the Netherlands Organization for Scientific Research (NWO), a new centre for society and genomics has been founded. The aim in launching the centre was to create a bottom-up network uniting scholars in the fields of society and genomics. Rather than just controlling or compensating for the implications of genomics, social scientists intended to bring their own expertise into the dialogue with bioscientists. However, in the final stage of founding the centre, this aspiration was nipped in the bud. As a result, the centre's research agenda has become primarily governed by the aim of adequately implementing genomics in society. The study of more complex relationships between science and society has been relegated to the background.

Marli Huijer is Senior Researcher in Philosophy at the University of Groningen, and Opzij-Professor in Gender and Biomedical Sciences at the University of Maastricht. She is the author of *De kunst gewoon te leven: Aids en de bestaansesthetiek van Foucault* (On Aids and Foucault's aesthetics of existence) (1996), and the co-author of *Factor XX: Vrouwen, eicellen en genen* (On women, egg cells and genes) (2004). She is currently writing a book on genomics and the construction of time. She has published on a variety of philosophical and bioethical subjects in journals such as *Philosophy and Social Criticism*, *Academic Medicine*, *Journal of Medical Ethics* and *Science Communication*. As President of Grensgevallen, a foundation that stimulates interaction between art and science, she has co-organized major public events in which the barriers between scientists and artists were put under strain.

Dutch Centre for Society and Genomics

In response to a call from 40 life scientists, in 2001 the Dutch government decided to set aside €189 million to reinforce the knowledge and infrastructure of genomics research. About 4% was earmarked for the study of ethical, social, economic, psychological and legal aspects of the genomics programmes. An independent task force, the Netherlands Genomics Initiative (*Nationaal Regie-Orgaan Genomics*), was founded to govern the new genomics infrastructure. It decided that, in addition to the existing NWO programme on the Societal Component of Genomics Research (which became part of the Netherlands Genomics Initiative), a Dutch Centre for Society and Genomics (CSG) would be founded. Strikingly, the international jury that was to decide which expressions of interest were to be worked out as a full proposal, chose a network proposal headed by Radboud University, Nijmegen. Unlike the other proposals, the network opted for a bottom-up approach, with expert groups at each university and a core group with all the expert groups represented. Establishing a common agenda allowed the expert network of social scientists—which included scholars in science and technology studies, psychologists, ethicists and others—to broaden the scope of their activities and focus on decisive societal issues. The input of genomics, politics, NGOs (non-governmental organizations) and the public in general was to be guaranteed by an advisory board of genomics researchers, policy-makers and representatives of patient, consumer, animal welfare, environmental and religious organizations. The international jury found the option of a really coherent network to be a promising one.

At the first meeting after the network was launched, new experts—including bioscientists, epidemiologists and physicians working in the field of genetics—joined the network. The expansion did not seem to affect the bottom-up approach; the full proposal opted for the network approach (Zwart, 2003). In its evaluation of the full proposal, the international jury again applauded the idea of including researchers from various Dutch universities. In response to the report, the CSG in formation asked all the researchers to submit research applications.

Shortly before the CSG was to become a reality, the proposed CSG director reported to the expert groups that the Netherlands Genomics Initiative (NGI) had its doubts about the bottom-up approach. The NGI found the agenda too open, the decision-making process too complex and the core group, with representatives of the participating universities, too large. Moreover, it wanted the agenda to be governed by important life science domains rather than the experts' local interests. As a result, in a top-down procedure, the CSG in formation decided to install a new core group with the authority to evaluate the research proposals. The projects the group selected were closely linked to research in the four recently established Dutch Genomics Centres of Excellence. The research topics included the ethical, psychological and social implications of large-scale screening programmes; the public perception of genomics in agriculture and food production; and the role of literary and artistic imagination in shaping the genomics future. The Netherlands Genomics Initiative appointed a supervisory board, including representatives from university boards, a science museum and the field of industry (www.society-genomics.nl). An advisory board was to be installed, including representatives from the four Centres of Excellence (*CSG Newsletter, 1*, December 2004). In the process, the CSG became an institute that draws up and initiates the societal as well as the research agenda. The initial dream of a bottom-up approach, with the agenda established by experts employed in genomics and society, was not realized.

Setting the research agenda

In response to the early history of the ELSI (Ethical, Legal and Social Implications) Working Group of the US Human Genome Project, commentators have cautioned that research on the ethical, social and legal aspects of genomics runs the risk of becoming compensatory, seeking to control the undesirable implications of genomics (Stemerding and Jelsma, 1996: 346). Based on her experience as chair of the ELSI Working Group, Lori Andrews concludes that to set its own research agenda, ELSI research needs an independent location and its own resources (Andrews, 1999: 184–206).

A recently published report on the ethical, legal and societal aspects (ELSA) of genomics in the Netherlands (Wouters, 2005) endorses this viewpoint: the more genomics is involved in setting the agenda on genomics and society, the more ELSA research seeks to control the implementation of genomics through compensatory measures and the less it is inclined to investigate more complex relationships between science and society. In the report, three types of research are distinguished:

(1) a society-oriented perspective focused on the impact of genomics on society and how to conduct scientific research in fruitful directions and solve societal problems;
(2) an application perspective focused on an unimpeded, though socially acceptable development and application of genomics;
(3) an explanatory perspective aimed at understanding innovation processes, interactions between users and producers, and how society in general responds to scientific and technological advances.

In the independent, peer-reviewed programme of the NWO, 28% of the projects are explanatory, 25% application-oriented and 47% society-oriented. In the CSG programme, the percentage of explanatory projects has dropped to 10%; 40% of the projects are application-oriented and 50% society-oriented. At the Centres of Excellence, which have recently started their own internal projects on society and genomics, the number of explanatory projects is zero; 90% of the projects are application-oriented and 10% society-oriented (Wouters, 2005: 19). Taking into account the close relationship between the Centres of Excellence and the CSG, and the termination of the NWO society-and-genomics programme, the number of application studies is expected to increase and the number of explanatory studies to further decrease.

This shift to implementation and application not only affects the research contents, it also has consequences for the disciplines involved in ELSA research. At the moment, the main players are science and technology studies (STS), ethics and psychology (Wouters, 2005: 29). Dutch STS scholars often opt for explanatory and society-oriented approaches. Their discourses are grounded in the social construction of science and technology and the co-evolution of science and society. However, most ethicists and psychologists prefer application and society-oriented approaches. Attention is devoted to an adequate implementation of science and technology. Patient autonomy and the principle of informed consent are the instruments generally invoked to ethically and psychologically govern new developments.

STS scholars have repeatedly argued that informed consent procedures reduce questions of the acceptability of science and technology advances to issues of individual choice. The

psychological and regulative bioethical approaches fail to yield a systematic analysis of the social transformations genetics and genomics produce. Science and technology are evaluated against the backdrop of the well-known relations between science and society. The unknown practices that can be generated by technology are not taken into account, as De Vries and Horstman note (2004: 188). Opposition to the informed consent approach is not only voiced in the world of STS, but also among health ethicists who lean towards different bioethical approaches, such as virtue ethics, narrative ethics and ethics of care. Life scientists, however, frequently prefer to cooperate with experts in regulative bioethics. Rather than question the hard core of science and its social implications, regulative ethicists are prepared to educate society on how to deal with genomics and instruct life scientists on how to behave in a socially responsible manner. Psychologists, in turn, are prepared to provide communication skills to responsibly apply genetic and genomic tests and technologies in healthcare.

The shift towards implementation brought about by the research strategy of the CSG and the Centres of Excellence will expand the involvement of ethics and psychology. Disciplines that favour a broader, more complex or critical approach, like STS, sociology, philosophy, economics, anthropology or history, do not benefit from this shift.

Does it matter? As long as the peer-reviewed NWO programme on the Societal Component of Genomics Research continues, social scientists will be able to enter the dialogue, starting with an agenda and expertise not solely governed by the implementation of genomics in society. The NWO programme is explicitly focused on the interaction between genomics and society's foundations and organizations, the self-image of individuals and how we deal with animals, nature and the environment (NGI, 2003, 2005). The idea recently behind the Arts and Genomics Centre, where new interfaces between genomics and art are explored, is an example of what is funded in this programme. However, the NWO programme will be terminated as soon as the current projects are completed. No follow-up of the research programmes has been ensured. The NWO programme committee does not have a say in the CSG research programme, which makes the social science researchers dependent on the non-peer-reviewed procedures of the CSG and friction is inevitable. The recent decision of the CSG to start a second series of research projects in 2006, after an open competition, might moderate this.[1]

A lost opportunity?

By abandoning the bottom-up approach and ignoring the value of peer-review procedures, the Dutch CSG lost the opportunity to create an exchange that would have been a fine platform for social and biosciences alike. As a result, two separate tracks operate under the umbrella of the Netherlands Genomics Initiative, one with the CSG initiating its own research, developing a societal agenda for future genomics research and functioning within the European research area on societal aspects of genomics, and the other with NWO

1 In 2004–2005, the CSG initiated ten projects. In 2006, an extra project will be conducted by the CSG. For the next nine projects, an open call for research proposals has been announced (*Society & Genomics Newsletter*, 5, September 2005). Four of these projects will be conducted in close collaboration with the Centres of Excellence of the NGI. Based on the nomination of an international jury, the CSG will decide which projects are liable for funding.

researchers performing their peer-reviewed studies and meeting each other in their own research networks. Each of the tracks has its own contacts with life scientists. Since the NWO programme is drawing to an end, the CSG will soon take the lead.

Why do I think the NWO approach is more promising for social and bioscientists than the CSG approach? For symmetrical interaction, it is crucial that bioscientists and social scientists each have their own research agenda before entering the dialogue. Otherwise bioscientists might easily opt for issues and experts that help facilitate the implementation and acceptance of genomics, and social scientists might well prefer research topics that suit the existing relations between science and society. To guarantee the content and quality of the social as well as the biosciences, it is important to start by acknowledging each other's scientific identity, expertise and views on which research questions are important, what counts as excellence and which tasks are to be performed.

Acknowledgements

I thank Hans Harbers and Robert Zwijnenberg for their comments. For editing, thanks to Sheila Gogol.

References

Andrews, L. (1999). *The clone age. Adventures in the new world of reproductive technology*. New York: Henry Holt & Co.

Centre for Society and Genomics. *Society & Genomics Newsletter*, 1(December 2004), *2*(January 2005), *3*(April 2005), *4*(June 2005), *5*(September 2005), *6*(October 2005).

NGI (Netherlands Genomics Initiative) (F. Biesboer) (2003). *Genomics, dreams, fears and fantasies: Public embedding of genomics research*. The Hague: NGI.

NGI (Netherlands Genomics Initiative) (A. van de Graaf) (2005) *Research between laboratory and society: Bridging the gap between the developers and users of genomics knowledge*. The Hague: NGI.

Stemerding, D. & Jelsma, J. (1996) Compensatory ethics for the Human Genome Project. *Science as Culture, 5, 3*(24), 335–351.

Vries, G. de & Horstman, K. (2004) *Genetica van laboratorium naar samenleving: De ongekende praktijk van voorspellende genetische toetsen*. Amsterdam: Aksant.

Wouters, A. (2005) ELSA Onderzoek in Nederland. *Het Nederlandse onderzoek naar ethische, juridische en maatschappelijke aspecten van genomics*. Nijmegen: Centre for Society and Genomics.

Zwart, H.A.E. (2003) *Full proposal: Centre for Society and Genomics*. Nijmegen, 4 September.