Maud Radstake
Centre for Society & Genomics
Institute for Science, Innovation & Society ISIS
Radboud University Nijmegen, P.O. Box 9010, NL-6500 GL, Nijmegen
tel. +31-24-3652731
radstake@society-genomics.nl

Bart Penders
Department of Health, Ethics & Society
Care & Public Health Research Institute CAPHRI
Maastricht University, P.O. Box 616, NL-6200 MD Maastricht
tel. +31-43-3882457, fax. +31-43-3670932
b.penders@zw.unimaas.nl

Inside genomics: the interdisciplinary faces of ELSA

Editorial for the thematic section on Genomics & Society

Obesity, malnutrition, cancer, crime, poverty and global warming are only a few examples of the many societal issues currently addressed by scientific research. Research into mechanisms of bodily fat storage, biotechnological improvements of food quality, the use of DNA-techniques in forensic science, the study of possibilities for crop improvement or for bio-fuels all involve *genomics*: the large-scale study of genes, proteins and metabolites (of humans, animals, plants or micro-organisms) and their functions and interactions among each other and with their environment. Life scientists from various fields and disciplines are involved in genomics research. The Human Genome Project was one of the first examples of 'big biology', involving sophisticated instruments, large sums of money, and many researchers thinking and working together in (often large) interdisciplinary projects.

With the launch of the Human Genome Project in the USA in the early 1980s, scholars from the social sciences and humanities became part of the genomics infrastructure. James Watson, the first director of the Human Genome Project, not only discovered the structure of DNA (Watson & Crick, 1953) but also invented ELSA[1]: the study of the ethical, legal and social aspects of genomics. It has been suggested that Watson advocated ELSA in the Human Genomics Project "not to set ethical standards but to let the science proceed

[1] Also known as ELSI: ethical, legal and social issues.

unimpeded" wanting "a group that would talk and talk and never get anything done"(Fortun, 2000, p.3).[2] Indeed, ELSA programmes have been widely criticized for being non-confrontational handmaidens of genomics research, with little (if any) effect on policy making.

The idea of ELSA genomics, however, found fertile ground and has travelled around the globe. The Netherlands Genomics Initiative,[3] for example, has included research into and communication on societal aspects of genomics from its start in 2002. ELSA has been included in the interdisciplinary field of genomics that covers genetics, microbiology, bio-informatics and epidemiology, among others. Like its object of study – genomics – ELSA has been institutionalized as an interdisciplinary field. It involves scholars originating from various social sciences and humanities, including (bio-)ethics, law, social psychology, sociology and science & technology studies. Its 'double' interdisciplinarity (i.e. in terms of both research object and subject) is what makes ELSA genomics a particularly *happy hunting ground* for the GJSS.

Naively, one might consider ELSA research to be part of the social sciences and humanities, and genomics to be part of the natural sciences. Yet discriminating between social and natural sciences is not always self-evident. Epidemiology, for instance, is part of genomics, yet it exists on the boundary of social and natural science. ELSA genomics is not merely 'the next in line' in the social studies of science. One of its most interesting characteristics is its intricate entanglement with its object of study. ELSA genomics, being funded as a *part of* genomics research programmes, is as much the subject as it is the object of its own research.

In this thematic section on genomics and society we present two research papers and a book review. The papers result from presentations given at the CORSAGE Winter Meeting *Genomics and Society: chances for true love?*,[4] organized by Bart Penders, Rens Vandeberg, Wouter Boon and Erik Aarden. CORSAGE is a Dutch group of young researchers studying social aspects of genomics. It is a thematic cluster of GeNeYouS, the Dutch Genomics

[2] These and other 'Watsonisms' are included and - more importantly - analysed, in Fortun (2005).
[3] The Netherlands Genomics Initiative or Nederlands Regie-Orgaan Genomics (NGI) is a taskforce that coordinates and stimulates genomics research in the Netherlands and manages the bulk of the Dutch research budget for genomics research.
[4] Organised in Utrecht (NL) on December 16, 2005 by the Cooperative Researchers on Society and Genomics (CORSAGE) and the Postgraduate Forum on Genetics and Society (PFGS)/Benelux Region.

Network for Young Scientists. Here again, junior researchers in humanities and social science are part of a network of mainly young life scientists.

In her book *Designs on Nature. Science and Democracy in Europe and the United States*, reviewed in this issue by Erik Aarden, Sheila Jasanoff discusses societal debates around biotechnological developments as articulations of political culture in different countries. An important issue is the formation of boundaries between 'science' and 'society'. It provides a relevant background to the research papers by Penders and Vroom, who challenge the boundaries between social and natural sciences. Both papers are about food: an issue that has evoked descriptive as well as prescriptive approaches, presenting knowledge about the relationship between people and their diet, as well as suggesting to people what (not) to eat.[5] Furthermore, food has always been distributed asymmetrically among geographical areas and social classes. Both Vroom's interest in agricultural food production and Penders' focus on nutrition exemplify the cultural, social and economic importance of food.

In his paper, Wietse Vroom (2007) explores how critical and constructivist theories of technology development articulate the political and ideological nature of agricultural biotechnology development in less developed countries. To approach technologies as value-laden aggregates of socio-technical ensembles rather than as neutral tools, implies a particular approach to development, which can be applied to the (trans)formation of local biotechnological practices. It is an approach that puts endogenous technology development over technology transfer, and participatory methods over advice and consultancy. Technologies cannot simply be handed over from one context to another. That is not only a matter of socio-economical, historical and cultural context; it lies in the material design of a technological application as well. Although the paper largely reflects the idea that technology development is an "inherently social process", we think that Vroom's approach is particularly promising because of the multidisciplinary training of the author. Trained as a life scientist, Vroom has the expertise to deal with biotechnological matter, which he takes into his work as a social scientist. Although the idea that technologies 'act' goes without saying in most of contemporary science and technology studies, it takes more than social science or ethics to describe and understand technological agency and politics, and even more to find a 'room for

[5] For historical examples and anecdotes, see Shapin (2002, 2004, 2006).

maneuver' to (trans)form biotechnology and genomics developments – by not *merely* attending to ethical or social aspects.

The next paper (Penders, 2007) presents an example of ELSA genomics research in western practices of nutrigenomics research. Bart Penders focuses on a specific controversy in nutrigenomics, being the development of 'the personalized diet'. He reviews scientific and societal expectations and practices to find out whether and how they fit. He concludes that they do not. In his analysis of this mismatch, Penders also take ELSA genomics as his object of research. ELSA researchers have actively been involved in the (ethical) debate around 'personalised nutrition'. Penders argues that the debate has not kept pace with scientific developments that have shifted the notion of 'personalised'. He describes the political agenda of nutrigenomics research as a 'politics of classification' and argues for an ethical agenda that addresses the politics of nutrigenomic practice, rather than merely nutrigenomic expectations. As Vroom, Penders has been trained as a life scientist. Is this why he was able to identify the weak spots in ELSA research on this issue?

The interdisciplinarity of Penders' and Vroom's contributions is more profound than their research object and focus. Both authors are ELSA researchers with a disciplinary background in the life sciences. Both advocate a participatory methodology, although not very explicitly in Penders' paper.[6] As cultural insiders, they appear able to 'unlock' a larger part of genomics practices than ELSA researchers outside of genomic practice. To clarify this point, we have included figure 1. It shows a conceptual matrix with four quadrants, loosely drawn from one presented earlier by Pearson (2001, p.59). Each quadrant represents a portion of the information or empirical material contained in a practice. The full circle represents all information in the practice and the division in four equal parts is completely random. Quadrant 1 represents ubiquitous information, readily accessible to all, whereas Quadrant 4 represents information hidden, accessible to none. The quadrants of interest are 2 and 3, representing the information accessible only to insider or outsider, respectively. Penders and Vroom are both insiders and outsiders to the practices they study. They have spatial, material, cognitive and normative access to the culture of genomics, i.e. the ability to participate, yet they also act as observing outsiders. Hence, they have access to, as well as the ability to act in three quadrants, whereas insiders or outsiders are restricted to two.

[6] Penders' work is based on extended periods of participant observation in various nutrigenomics practices (see Penders, 2006).

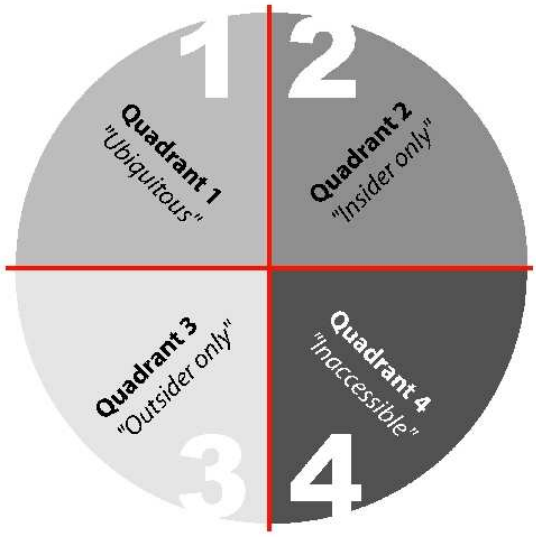

Figure 1, Access to practices. **Four quadrants representing different levels of access to a research practice can be distinguished. Figure redrawn from and based upon figure 1 entitled 'the insider-outsider position' (Pearson, 2001, p.59).**

Interdisciplinarity is a frequent topic for discussion in the ELSA genomics community, referring both to interactions between scholars from various social sciences and humanities, and to interactions between ELSA research and life science. Ultimately, ELSA's mission is transdisciplinary, including societal actors in science and technology development. Of those, interactions between life scientists and social scientists seem to be among the hardest to achieve.[7] Yet for ELSA to actually get something done – despite Watson's intentions – it is vital. Scholars like Vroom and Penders can serve as role models here. Considering science and technology as social and political practices, they do not neglect their materiality. More than their colleagues with degrees in ethics or social science, they are equipped to address genomics not only as a matter of people, papers and ideas, but also of food products, personalized diets and plant crops. Their work shows that being a (good) life scientist is an advantage in doing ELSA research. That advantage may outweigh possible disadvantages such as blind spots or unchallenged self-evidences.

Penders' insiderness allows him to be a reflexive observer of both nutrigenomics and ethical research. What is more, his results are taken seriously by life scientists, considering

[7] Cf. Snow (1993).

his recent publication of a critical discussion paper in a nutrition science journal (Penders et al., 2007).[8] Something similar could happen in the next stage of Vroom's project. Working interdisciplinarily fosters a critical approach to commonly accepted scientific, social-scientific and ethical methods, theories and concepts, since the focus is on the *issues*.[9] For the purpose of not merely describing but also improving relations between genomics and society, reflexive 'handmaidens' could contribute more to the social robustness and scientific relevance of ELSA genomics than critical outsiders could. Both Vroom and Penders explore methods and theories for an interactive social science, which is a condition for the societal embedding of genomics. Moreover, they present original, challenging and exciting research that presents the actual matter of genomics in its multifaceted setting..

We neither argue that all ELSA researchers should have a background in life sciences, nor that all ELSA research should be embedded or interactive. To prevent becoming instrumental and uncritical ('going native'), ELSA also needs conceptual clarification and imagination. Therefore we advocate the co-existence and continuous co-development of 'traditional' critical outsider approaches by social scientists and ethicists, and of innovative insider-approaches as taken by Penders and Vroom, within the ELSA framework. Embedding genomics in society requires the mutual inclusion of life sciences, social sciences and humanities, evoking innovative scientific approaches as well as comprehensive strategies for coping with contemporary societal issues.

References

Fortun, M. (2000). "Where do we draw the line? Lines in the sand of life". *Isis Reconstructive Science Journal* **1**(1): 1-8.

Fortun, M. (2005). "For an ethics of promising, or: a few kind words about James Watson." *New Genetics and Society* **24**(2): 157-173.

[8] Doing interdisciplinary research does not necessarily imply writing for interdisciplinary audiences. Penders demonstrates this by publishing two papers with a comparable argument for two different audiences: the paper in this issue targets social scientists, whereas the paper referred to, addresses nutrition scientists.
[9] See e.g. Leonelli (2005, p.2).

Leonelli, S. (2005). "Editorial: Pluralism and Normativity in Interdisciplinary Research." *Graduate Journal of Social Science* **2**(1): 1-6.

Pearson, J. (2001). ""Going native in reverse": the insider as researcher in British wicca." Nova *Religio* **5**(1): 52-63.

Penders, B. (2006). "Over volgen en gevolgd worden: Participatie, interactie en interventie in nutrigenomics." Lecture at the *NWO Societal Component of Genomic Research*, Nov. 30th, Ede, NL.

Penders, B. (2007). "Aligning nutrigenomics and ELSA. Towards a politics of classification." *Graduate Journal of Social Science*, 2007 vol. 4 special issue 1: 34-49.

Penders, B., K. Horstman, W. H. M. Saris and R. Vos (2007). "From individuals to groups: a review of the meaning of 'personalized' in nutrigenomics." *Trends in Food Science & Technology*.

Shapin, S. (2002). "Barbecue of the vanities: a short history of diet books." *London Review of Books* **16**: 21-23 (Selected as the LRB Essay and published online by 'The Guardian Unlimited').

Shapin, S. (2004). "The great neurotic art." *London Review of Books* **26**(15).

Shapin, S. (2006). Eat and Run. Why we're so fat. *The New Yorker: The Critics - Books*.

Vroom, W., G. Ruivenkamp and J. Jongerden (2007). "Articulating alternatives: Biotechnology and genomics development within a critical constructivist framework." *Graduate Journal of Social Science*, 2007 vol. 4 special issue 1: 11-33.

Snow, C.P. (1993). *The two cultures*. Cambridge: Cambridge University Press.

Watson, J.D. & F.H.C. Crick (1953). "Molecular structure of nucleic acids: A structure for Desoxyribose Nucleic Acid." *Nature* **171**(4356): 737-738.