

Editorial

Although this is a non-themed issue, the focus of the papers and reviews collected in *Genomics, Society and Policy* 5.1 clearly tend to converge towards a common theme that, apparently, has become a major and urgent item for reflection and deliberation within our field, namely the way in which genomics research agendas tend to evolve, notably the extent to which they allow themselves be targeted towards addressing urgent societal issues as well as the extent to which they allow “upstream” involvement and participation from future stakeholders representing various sections of society.

Helen Wallace takes up this theme from a historical perspective, reflecting in a detailed manner on the way in which the tobacco industry, through research funded by the *Council for Tobacco Research* (CTR), invested in the identification of oncogenes responsible for causing lung cancer, so as to downplay the more general causal link between lung cancer and smoking habits, focusing attention instead on a minority of smokers, carriers of a genetic disposition that made them more prone than others to developing cancer. This theme (the identification of a sub-section of smokers exceptionally susceptible to developing cancer and other health problems) was later taken up by the Human Genome Project. Wallace concludes that during the past decades, major research investments have been conducted in accordance with agenda priorities of tobacco companies. She argues that in the future more democratic and transparent decisions about research funding priorities are required.

The paper by Bovenberg et al focuses on the governance of biobank research and how this type of research may further develop in the future. Biobanks are uniquely positioned when it comes to translating population-based health data into “personalized” bioinformation. In order to explore the future development of this research, a fictional court case is designed, in which a number of emerging ethical and legal issues are addressed. In the paper by Fortin and Knoppers, a similar issue is addressed, this time focusing on the research into the relationship between asbestos exposure and lung cancer. The authors argue that although this research has clearly improved the health perspectives of workers in construction practices, such research could not have been conducted in the normative landscape of the present, notably because of restrictions on secondary uses of bioinformation (the deployment of databank information for other questions than those initially addressed). This raises the question whether current regulations (current practices of governance of research infrastructures such as databanks) are optimal when it comes to addressing the emerging promises and challenges of population research. Finally, two other contributions (by Patra et al and Suda et al) address similar issues but in a different socio-cultural context, namely in India and Japan. Patra et al discuss some of the impediments or hindrances encountered while exercising the principle of informed consent in the context of genetic and genomics research among the tribal and rural caste communities in India (hindrances such as illiteracy, poverty, paternalistic attitudes, sociocultural barriers, ineffective regulatory mechanism and procedural inconsistency, among others). The authors conclude that, although the sociopolitical landscape in India contains major challenges for the implementation of informed consent in genomics research, it is nonetheless important that informed consent remains part of the normative infrastructure for governing future research

developments and agenda-setting in the area. In the paper by Suda et al it is indicated that, although Japan made a major contribution to large-scale genomics research activities, such as the sequencing of the human genome, less than 1% of the research budget involved has been devoted to ELSI or ELSA research. It should not come as a surprise, therefore, that, whereas in many other countries public engagement in science and technology has grown in importance as developments in science and technology make increasingly significant impacts on people's lives, public involvement in Japan is rather sparse. This is analysed in the context of the International Haplotype Mapping (HapMap) Project as a case study.

The common theme of agenda-building and societal involvement is present in our book reviews section as well. Bart Penders reviews a fascinating thesis by Niki Vermeulen on the emergence of big science in biology: the projectification of biology through the implementation of large-scale research endeavours, encompassing all zones of life, from oceanography down to virology. Marli Huijter reviews Paul Rabinow's recent monograph *Marking Time*, a reflection on how a philosophical anthropologist should respond to the acceleration of pace as a key feature of contemporary research agenda's in the life sciences (apparently by becoming overtly productive and prolific at an equally high pace himself). Last but not least, Ursula Naue reviews *Limits to Governance*, reflecting the output of genomics and society research by the ESRC Innogen Centre at Edinburgh. The volume presents a multifaceted approach to governance of the life sciences. Its main objective is to provide a critique to the new governance agendas for science and innovation as emerging in the context of the life sciences, notably genomics. In her review Naue notably addresses some of the conceptual issues involved as well as the development of "a creative set of alternatives" for current governance practices as a task for the future.

Thus, this GSP issue reflects in a lively manner how the ELSA genomics research community is taking stock of the outcomes of our work so far, notably concerning some of the major issues (governance of "big" life science research, secondary uses of bioinformation, informed consent procedures in a global context etc.) that need to be taken up again in the context of emerging life sciences agenda's of the near future.

Hub Zwart

Centre for Society and Genomics, Radboud University Nijmegen, the Netherlands