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International Corsage Winter Meeting in Nijmegen, NL

Genomics in the Policy Room

3 December 2008, 9.30 – 17.30 hours

ABSTRACT BOOKLET

In the “policy room” negotiations about how to deal with genomics affect the work of both life-scientists and social scientists accompanying genomics programmes: On the one hand, genomics is dealt with as an *object of policy-making*, most commonly in terms of (future) regulation & implementation, and in science policy. On the other hand, *policy-making* is also on the agenda of those active in genomics. Important policy questions are, among others, the division of resources, the valorisation and patenting of research findings and the societal aspects of genomics. The meeting is designed as a forum for young (pre/post-PhD level) scholars and practitioners at the junctions of science, social sciences/humanities and policy-making.

Please, register by sending an email to:

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The meeting is organized by Peter Stegmaier, CSG Nijmegen, & Erwin van Rijswoud, Department of Philosophy and Science Studies, Science Faculty, Radboud University Nijmegen in cooperation with Eline Huisjes and Jurgen Haanstra from **GeNeYous** (the Genomics Network for Young Scientists; www.geneyou.nl/home.php) and also with the **Postgraduate Forum on Genetics and Society** (PFGS, based in Exeter/UK; www.pfgs.org/pfgs). Corsage is a thematic cluster of GeNeYous. See also: www.geneyou.nl/corsage/ and www.society-genomics.nl/?page=640. With financial contributions by the Centre for Society and Genomics (CSG), and the Netherlands Graduate Research School of Science, Technology and Modern Culture (WTMC).



Kate Attfield, Cardiff University, UK

Does research on the 'deaf gene' reinforce imposed Deaf identification?

Studying the 'deaf gene' arguably means biologising Deaf (who use a signed language) people's existence. It means reinforcing normative values of 'normal ability and functioning' - that *we can hear*; subsequent policy 'evidence' thereby rejects recognition of diverse culture and language identity, and *alternative* 'normal functioning'. The British Human Fertilisation and Embryology Bill section 14, 4, 9 fundamentally sets out aims to delete the deaf gene, and thereby to protect Deaf people from existence. The societal status and recognition of British Deaf people (who sign British Sign Language), is effectively of collective invisibility. The welfare system defines Deaf people as individuals with impairment and need, legislation which may only reflect the ideological norms of society as a whole - of hearing cultural determinism, of need for speech and hearing, and of these 'objectified' values.

A recycled argument based upon biologism lends weight to the 'evidence' of a primary medical identity and non-culture of Deaf people. Public policy does not aim at a consideration of Deaf people – instead Deaf people are slotted into general policies for disabled people, or for people with 'special needs'. Where Deaf people attempt to negotiate independent public access and contribution, they are automatically referred to the welfare system. In contrast Deaf people campaign for a BSL language Act, where their language (and identity) can be protected and promoted. Societal recognition of Deaf people through the strategic framing of culture inequality as a policy problem, and the subsequent culture mainstreaming of public policy could ensure redistribution. Genomic research may credibilise medical 'solutions' to 'deafness'. Will scientists be permitted to focus their attentions elsewhere?

Martin Boeckhout, University of Amsterdam, NL

Tracing transnational biobank governance: an issue-based approach

Biobanks are often claimed to be crucial to the future of genomics research. Many parties, such as researchers, government officials and other parties involved in biomedical research have invested their hopes and resources in this burgeoning field. Recent developments focusing on forging pan-European or even global collaborations between biobanks have only added to these dynamics, raising a number of ethical, legal and social issues – such as those related to privacy and commercialisation of research. Resolving these issues, according to most scholars, will require a new set of governance mechanisms.



Biobanks, however, are not stable practices amenable to clear-cut policy interventions. Therefore, the shape biobank governance should or could take cannot be answered in a straightforward manner. Both the objects (what exactly are biobanks?) as well as the constituencies involved in governance (by whom, in what ways, can they be governed?) are shifting. Government officials, bioethicists and other ELSA scholars are part and parcel of these dynamics: they help configure the governance of biobank infrastructures, even if their contributions do not straightforwardly have the intended outcomes.

Studying the processes through which biobank governance acquires its shape, therefore, calls for an approach which takes these uncertainties and contingencies directly into account. This presentation will argue for an approach which puts issues center stage: the different problematics and expectations in which various actors find themselves mutually implicated. Tracing the processes in which such emerging issues are articulated gives us a different view of how biobank governance gets constituted and allows us to reformulate the contribution policymaking and ELSA research could make to the emergent field of biobank governance.

Koen Dortmans, CSG Nijmegen/Lux Nijmegen, NL

How can public debates influence policy agendas, if at all?

Public debating centres have gained ground in The Netherlands for the last ten years. Together with the science cafes, which entered the public sphere since 2004, science and technology have found their way to a broad audience. This development fits perfectly in with the growing awareness of interactive science communication of recent years.

Still it is doubtful whether public debates can really be considered as a part of the colourful spectrum of the countless initiatives of the so-called 'participatory turn' of the Public Engagement with Science (PES) which arose since the late 1990s. Now most "public debates" on science and technology still seem to be based on the deficit model: organizers offer scientists a venue and stage to let them explain the technical details of their research and stress their unchallenged views on the societal importance of their work in order to improve the public understanding of science.

Is it possible to reshape public debates into democratic agorae, i.e. as dialogues which allow issue articulation in order to address co-produced knowledge of affected publics and scientists on the societal embedment of genomics to policy agendas?



Steven Flipse, Dept. of Biotechnology, Section Biotechnology and Society, TU Delft, NL

LIFE to LEGO: Policy issues for students in the open source, synthetic biology, student competition, called “iGEM”

Synthetic biology is a novel approach towards Genetic Engineering practice: it takes recombinant DNA techniques to the extreme and only the sky seems to be the limit. Even students from different scientific disciplines can currently participate in real life synthetic biology research: within the iGEM (international Genetically Engineered Machine) competition, organized by the MIT in Boston, undergraduate student teams compete for designing and engineering the best micro-organism based innovation. By standardizing biological parts the students try to build biological systems within the labs of their universities, while sharing their findings in an open source database hosted by MIT. Once a year all teams are to present their work during a festive event in Boston.

But one can wonder whether this standardized approach towards biology is really a “good” or “beneficial” development. The novel character of standardized, synthetic biology and the open source approach brings new ethical questions, on top of the ones already present in genetic engineering. For example: how “synthetic” can “biology” be? Also consider the recent quarrel between the Dutch minister Plasterk (of Education, Culture and Science) and minister Cramer (of Environment and Spatial Planning). The two ministers could not agree on whether or not synthetic biology research was such a novel approach that it would need new regulations. This discussion is still going on.

Apparently the (moral) issues relating to synthetic biology also encompass questions of policy: biological safety and security in the biological open source approach have been unknown to our political system up until now. And what about intellectual property rights? This study has focused on the attitudes the TU Delft iGEM participants towards issues in Synthetic biology, including issues regarding policy like open source and intellectual property, responsibilities in intentional or unintentional misuse, etc. The findings of this study relevant to the topic of this symposium will be presented and discussed.

Roel Nahuis, Innovation Studies Group, Copernicus Institute for Sustainable Development and Innovation, Utrecht University, NL

Why genomics implies a reconceptualisation of user involvement.

A fashionable way of studying user involvement in medical research is translational research. Translational research is seen as a phase in the knowledge chain. It comprises the steps from identification of possible leads (in patients or patient material) for diagnostics, prevention or treatment, to early application in clinical practice. Clinicians are seen as the primary users of medical knowledge. In this presentation we address the question how this notion of translational research can be extended to also include the role of end users, such as patients and patient groups. More specifically, we explore the question whether the vision of personalised medicine does not necessitate such an extension.



After arguing that the model underlying this notion of translational research is essentially linear and has a blind spot for the role of end users, a distinction between a 'design-centred' and a 'social learning' perspective on user involvement is introduced. In contrast to the first, the second perspective starts from the assumption that technologies are essentially 'unfinished' when they enter the user environment and emphasizes the active role of intermediate and end users in the configuration and domestication of innovations.

The emergence of genomics is said to be characterised by four trends: (i) more emphasis on screening and diagnostics, (ii) from illness-based to risk-based characterisation of 'patients', (iii) from trial and error to specific targets, and (iv) from one-size fits all to customisable therapies/diets. These trends can be summarised by the notion of 'personalised medicine'.

Experience from ICT learns that such trends towards personalisation trigger a shift from the design-centred towards the social learning perspective on user involvement. The question whether this is also likely to happen in genomics is explored with the examples of Herceptin and commercial self-tests. The Herceptin example shows that what is often called personalised medicine is in fact stratified medicine. Stratified medicine is quite well understood from a design-centered perspective. For commercial self-tests, a social learning perspective is much more relevant. Whether these tests will become accepted depends on how people will domesticate these tests, how they find ways to deal with new dilemmas in the private sphere and how this will impact on the cultural level. An extended understanding of translational research will be necessary to capture these domestication processes. Whether the design centered perspective or the social learning perspective is more adequate should be judged on a case-by-case base

Imme Petersen, FSP BIOGUM, University of Hamburg, Germany

Debating disclosure and confidentiality in clinico-genomic research

In clinico-genomic cancer trials tumor tissue is analyzed to identify genetic components which are involved in cancer development, reaction to treatment and prognosis. Though genetic factors may influence these processes, they do not cause them in the narrow sense of the term. Therefore, the clinical relevance of research findings is difficult to evaluate. In the academic discourse the ethical and social implications as well as requirements of confidentiality regarding the disclosure of clinico-genomic findings to patients are controversially discussed: Should clinico-genomic information that has only *the potential* to be clinically relevant be returned to patients? And if yes – what kind of regulations have to be fulfilled to guarantee data protection?

According to ethical guidelines and legal regulations from Europe and the United States, there exists no obligation for such an individual donor feedback. This paper therefore discusses what kind of difficulties have to be faced by returning results of clinico-genomic research to persons concerned. These are in particular the probabilistic character of genetic information and the pleiotropic nature of genes (what to feed back?); the potential impact of genetic information on family relationships and reproduction (to whom to feed back?); the potential impact on interests of other family members (who feeds back?); and the increasingly prevalence of genetic research in common disorders such as cancer (how to organize feedback?). By suggesting some conditions that should be fulfilled for the disclosure of individual clinico-genomic research re-



sults to research participants and their families, this paper will attempt to give guidance in the debate of duty to return research findings – for clinical as well as political decision-making.

Tilo Propp (presenter), Ellen Moors and Marjolein van der Klauw, Department of Innovation and Environmental Sciences/Innovation, Studies Utrecht, Utrecht University, NL

Report on a scenario building exercise

In this presentation we will report on results of a scenario building exercise addressing current developments in Dutch colorectal cancer and epidemiology and how these could affect future cancer healthcare scenarios. We will link these results to two topics of the 2008 Corsage winter meeting, ie ‘What are the genomics policy issues at stake today...?’, and ‘By which means and in which ways do researchers and policymakers negotiate their perspectives and interests?’

The scenario workshop will focus on the current relationships between cancer genomics and epidemiology in terms of funding and research design. The true potential of tools such as high-throughput genetic expression profiling applied in molecular genetics and genetic epidemiology is far from being articulated, and is often expressed in terms of uncertain product and scenario expectations, such as ‘targeted therapies’ and ‘personalized health’. The future of genomics is at stake in the sense that without high and sustained investments, we will not know what genomics will be able to deliver. However, the shift towards genomics moves funds away from research projects with non-genomic components. The benefits of genomics and geneticized perspectives on disorder aetiology and healthcare threaten to become the losses of population level prevention. Thus, where genomics is at stake, other life sciences fields are – in a different way - also at stake; genomics does not exist in a world on its own, neither for policymakers nor ELSA researchers. Current life sciences developments can have detrimental effects on the development of the multi-disciplinary knowledgebase underlying visions of future cancer healthcare, expressed in terms of ‘integrated care’ or ‘life-course perspectives’. Scenarios are means by which researchers and policymakers negotiate their perspectives and interests, and in our scenario exercise we will explore these possible effects broadly, covering research, innovation and healthcare. The recommendations we aim to draw up will not be limited to genomics programme coordinators, but all actors who have a stake in healthcare.

Daniel Puente-Rodríguez, Critical Technology Construction (CTC), Social Sciences Group, Wageningen University, Athena Institute, Faculty of Earth and Life Sciences, Vrije University Amsterdam

Local Sustainable Biotechnological Developments: The Territorialization of Genomics

Within academic and policy circles the transfer of technologies is acknowledged as a process that brings about development. Today, the agrarian applications of genomics in the territories inhabited by resource-poor farmers are approached from this perspective. Nevertheless, genomics has been developed within environments with large technical capacities. Therefore, the application of genomics aimed at strengthening resource-poor farmers’ systems emerges as a difficult task.

Strong top-down social and technological designs (which are at the core of the ‘transfer of technology approach’) planned by policy makers fail because of two main reasons. Firstly, be-



cause of their *functional understanding of territories* and the subsequent treatment of territories as impersonal and abstract places without cultural specificities. Secondly, they fail because they usually understand technology as just a material entity which has no relation at all with any kind of social matter.

Besides, and in different way, they fail also because usually socio-technical processes depend on a large set of improvisations and informal practices that can not be codified and which are specific to the local context.

My PhD research project is based, among other things, on the study of case studies where the development – from the bottom-up – of genomics in particular and of biotechnologies in general is strengthening the developmental capacities of peasant's agrarian systems, and empowering peasants within the genomics systems themselves. For this purpose, I have studied three cases at three interrelated analytic domains: The territorial, the technical (technological redesign), and the domain of reterritorialization. This three level concept is labelled as '*local sustainable biotechnological development*' and concerns a type of development that enhances the local human and natural resources of a territory, and is based on the re-construction of biotechnologies mainly (though not exclusively) by and for the locality. During my presentation at our fourth Winter Meeting I will introduce you to this *territorial approach* for the deployment of genomics for development.

Yrrah Stol, Centre for Society and Genomics, Nijmegen, NL

The Trend analysis Biotechnology: scientific trends and societal relevance

Since 2004, a 'Trend analysis Biotechnology' (trendanalyse biotechnologie) has been published in The Netherlands once every two to three years. This report is an essential aid for politicians and policymakers for decision-making and parliamentary discussion on issues relevant to biotechnology-policy, for instance in deciding on research grants and the future of regulation.

Trends in biotechnology and adjacent scientific fields are identified by the Commission for Genetic Modification (COGEM), the Commission Biotechnology Animals (CMD) and the Health Counsel (Central Committee on Research involving Human Subjects (CCMO) in first edition). Not all scientific trends are included in the analysis, however: a selection is made of those trends that are deemed 'societal relevant'.

The rationale behind this choice is that only the scientific trends relevant to society are relevant to politics and policymaking. However, the rationale may leave a number of questions unanswered. For instance, should basic scientific trends that have no direct field of application not also be a concern to policymaking in an anticipatory mode? And moreover, what does 'societal relevance' actually entail, and how can it be determined?

For the coming edition of the Trend analysis, the Centre for Society and Genomics will be responsible for the selection of those scientific biotechnology trends that could have meaning, or implications, for society. The presentation will go into the methods and concepts used to answer this important yet difficult question.



Victor Toom

How much justice can forensic DNA profiling handle?

During my talk I want to address some general issues related to my phd-research about forensic DNA practices in the Netherlands. Forensic DNA practices are, by definition, a domain where law and science meet. Looking at the Dutch context, one will learn that several forensic DNA laws have been enacted since 1994. Forensic DNA profiling is – by many – considered as the new gold standard where it concerns both evidence and crime investigation; in short, forensic DNA contributes to more justice, more truth and a safer society. From this perspective it seems very reasonable to enact other forensic DNA laws.

On the other hand, my study of forensic DNA practices (science, law, judiciary, crime investigation and the enactment of bodies and identities) suggest that long-held ‘immutable’ legal principles like inviolability of bodies, bodily integrity, privacy, being regarded as being innocent until proven guilty, and a well defined motivation for crime research are at stake.

These measures ‘for the common good’ may be explained from a technological deterministic or technological imperative framework (mere availability of technologies), and can be explained from a social constructive/deterministic framework (terrorism, safety, war against crime etc.). Although all these perspective seem to be able to explain ‘what is going on there’, I consider them as unsatisfactorily.

What I would be interested in, is to share thoughts and hear ideas about an underlying logic that favors crime-fighting technologies above enhancing long established and cherished civil rights.