SETTING THE AGENDA

# Genomics & Society

International Conference

**Amsterdam, 17th & 18th April 2008**

**Venue:** West-Indisch Huis (central Amsterdam)

**Organised by:** the Centre for Society and Genomics & the UK Economic and Social Research Council's Genomics Network.

# PROGRAMME OVERVIEW

## 16th April

| | |
|---|---|
| 20.30 | **Pandemonia science theatre** |
| 21.15 | Drinks |

## 17th April

| | |
|---|---|
| 08.30 | Registration |
| 09.30 | **Opening** **Schutterszaal**<br>Annemiek Nelis |
| 09.45 | **Plenary session 1** **Schutterszaal**<br>Peter de Knijff, Leiden University Medical Centre: 'Forensic genomics and interaction with policy-makers'<br>Peteris Zilgalvis, European Commission, 'Governance and ethics in genomics in the EU: reflection on interaction between experts, policy-makers and society' |
| 10.45 | Break |
| 11.15 | **Parallel session I** |
| 12.45 | Lunch |
| 14.00 | **Parallel session II** |
| 15.30 | Break |
| 16.00 | **Parallel session III** |
| 19.30 | Drinks |
| 20.00 | Dinner |

# PROGRAMME OVERVIEW

## 18th April

| | |
|---|---|
| 09.00 | **Parallel session IV** |
| 10.30 | Break |
| 11.00 | **Parallel session V** |
| 12.30 | Lunch |
| 13.30 | **Parallel session VI** |
| 15.00 | Break |
| 15.30 | **Plenary session 2** **Schutterszaal**<br>Darryl Macer, UNESCO, Bangkok, Thailand: 'The globalisation and internationalisation of ELSA genomics and bioethics'<br>Oron Catts, SymbioticA, University of Western Australia: 'Genohype, metaphors and direct engagement with the manipulation of life' |
| 16.30 | **Conclusions**<br>George Gaskell, London School of Economics, UK |

Society&GENOMICS Centre for Society and Genomics

ESRC genomics network

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**Design** Hannie van den Bergh (www.studio-hb.nl)

# PARALLEL SESSIONS I & II & III

## Schutterszaal

### Stream 1
### Genomics & Behaviour

### Session I-A

ELSA genomics research in psychiatry: results, requirements, and effects

*Ingrid Baart*

Ingrid Baart
From deep truths to wide networks: toward new ontologies and epistemologies in psychiatry
Vololona Rabeharisoa
Towards a new form of medical work in psychiatry genetics: the case of autism
Sabine Ootes
Psychiatric dis-orders: about genetic causes & social problems

### Session II-A

Sport genomics

Toine Pieters
Life cycles of doping products: Ways of regulating genetic doping
Ivo van Hilvoorde
DNA testing and biological passports in sport;
Full control of the 'pre-game contest'
Arno Müller
Ethical Aspects of the therapeutical application of gene technology in sports

### Session III-A

Behavioural genomics and the case of addiction: what about autonomy and responsibility?
*Johan de Jong*

Richard Holdsworth
Behavioural genomics and the case of addiction: what about autonomy and responsibility?
Ben van de Wetering
Addiction as a brain disease: policy and practical implications
Tom Walker
The implications of the brain disease model for ascriptions of responsibility to addicts
Johan de Jong
Addiction and autonomy: normative implications of the brain disease model

## Commandeurzaal

### Stream 2
### Biobanking

### Session I-B

Embryonic stem cell research: an analysis of the legal positions developed in the UK, Belgium, and Germany
*Jan Deckers*

Jan Deckers
UK Parliamentary debate on embryo research: what were the arguments, and how could the debate be improved?
Christine Hauskeller
Science Policy and its effects on scientific creativity - German and Japanese innovations regarding pluripotent cells
Bart Hansen
The search for ethically sound embryonic stem cells: a fool's errand?

### Session II-B

In the Bank? Critical Reflections on the Past Promises and Future Expectations of Biobanks
*Richard Tutton*

Richard Tutton
Banking Expectations: The Promises and Problems of Biobanks
Mina Bhardwaj
Gene-environment interactions and statistical validity: ethical concerns for biobanking
Miguel Garcia-Sancho
Towards a long history of sequencing: the practice of data gathering and the emergence of the first protein and DNA structural databases (1965-1985).

### Session III-B

Governance, Publics and Biobanks

*Richard Tutton*

Nadja Kanellopoulou
Normative Assumptions in Genomic Banking: Solidarity, Equity and Reciprocity
Gill Haddow
Deliberation and representation: diverse purposes and practices in exploring views about genetic databases
Catherine Heeney
Biobanks and Public Health: A comparison between the relationships of biobanks to the public health systems in the UK and France?

## Admiraalszaal

### Stream 3
### Genetic Testing

### Session I-C

Moving from monogenic to multifactorial disorders: implications for ethical, legal and social aspects of genomics in health care practices
*Carla van El*

Dirk Stemerding
Genetic susceptibility testing: a new technology implying new moral controversies?
Lidewij Henneman
Genetics and multifactorial disorders: Impact of using family history on motivation to prevent disease
Jan Lubinski
Susceptibility screening for cancer: the Polish experience

### Session II-C

Expanding neonatal screening: challenges for policy making

*Carla van El*

Daniela Freitag
The politics of neonatal screening.
Anne Marie Plass
Treatable and untreatable diseases in the neonatal-screening programme: the opinion of future parents in the Netherlands.
Amy Lloyd
Duchenne Muscular Dystrophy and reproductive decision-making: implications of newborn screening.

### Session III-C

Genetic testing

Anne Brüninghaus
Self-Perception and Decision-Making in Predictive Genetic Testing
Jyotsna A Gupta
Genetic testing and pregnant women's choices in India
Cecile Janssens
Predictive Testing for Multiple Genetic Variants in Common Diseases: A different ELSI landscape from testing for traditional genetic diseases

## Compagnieszaal

### Stream 4
### Methodology

### Session I-D

Digital ELSA genomics : Method or madness?

*Ruth McNally*

Richard Rogers
The Web as Resource, Source and Object of Study
M den Besten
Caught between epistemic practices and technological affordances: The story of Swiss Bio Grid
Brian Wynne
Patentomics: Mapping the Intellectual Property Landscape for Synthetic Biology

### Session II-D

Societal dialogue: from engaging citizens to setting agendas

*Maud Radstake*

Marian Deblonde
Co-creating nano-imaginaries: some reflections on substantial and procedural results
Alex Plows
Upstream engagement at the grass-roots: reframing the debating stakes
Maud Radstake
Interactive agenda-setting through dialogue: lessons from The DNA-Dialogues

### Session III-D

Engaging scientists

Jane Calvert
Contributor, collaborator or critic? The role of the social scientist in synthetic biology
Anke van Gorp
Informing the public or interacting with society; the impact of societal interaction activities on genomics research
Brian Rappert
Engaging with Scientists in Matters of Controversy: A Proposed Method

## Anti-chambre Admiraal

### Stream 5
### Governance & Innovation

### Session I-E

Ethical, Safety and Security Aspects of Synthetic Biology

*Alexander Kelle*

Anna Deplazes
Ethical implications of Synthetic Biology
Markus Schmidt
The Biosafety of Synthetic Biology
Alexander Kelle
Biosecurity Implications of Synthetic Biology - Between Awareness Raising and Policy Formulation

### Session II-E

Dynamics of genomics innovations and the role of users

*Ellen Moors*

Roel Nahuis
User producer interaction in context? The case of functional food innovation
Paul Martin
User-producer links and the socio-technical shaping of novel therapeutics
Wouter Boon
Demand articulation in emerging genomics technologies: the role of patient organisations

### Session III-E

Guiding Life Sciences Governance in the Age of Genomics

*Ellen Moors*

Joyce Tait
Appropiate Risk Governance of Innovative Technology in Life Sciences
Tilo Propp
Tools for aligning genomics innovations. Expectations of convergence on pharmaco- and nutrigenomics based ' personalized health'
Alex Faulkner
Technological zones and regulatory pathways: the snakes and ladders of tissue-engineered medical technology formation in the European Union
Femke Merkx
The role of hybrid forums in governing the introduction of novelties: the case of genetic testing and insurance selection

## Anti-chambre Compagnie

### Stream 6
### Genomics & Development

### Session I-F

Reconstructing Genomics Knowledge Systems for Development: Counter Politics in Agenda Setting?

*Joost Jongerden & Guido Ruivenkamp*

Shuji Hisano
Actuality and Potentiality of Ethical Reflections for Reconstruction of Biotechnology
Wilhelmina Quaye
Reconstruction of (bio)technologies and genomics in the context of food sovereignty
Daniel Puente Rodriguez
Energy for the poor? Reconstructing genomics and bio-fuels regimes

### Session II-F

Sharing the Benefits of Genomics with Developing Countries

*Wietse Vroom & Bram de Jonge*

Bram de Jonge
Sharing the Benefits of the Potato: From Peru to the Netherlands and Back Again?
Kyriaki Papageorgiou
Genomics Research and Agricultural Development: A View from the Nile
Wietse Vroom
Linking upstream genomics innovation systems with informal seed systems: the case of the Generation Challenge Programme

### Session III-F

Interaction And Boundary Crossing In Nutrigenomics

*Rens Vandeberg*

Bart Penders
Norms and Politics in Contemporary "Big Nutrition"
Rens Vandeberg
Interactive Learning in Nutrigenomics: A Comparison between The Netherlands and Germany
Sibylle Gaisser
Nutrigenomics at the interface of genetic testing, pharmacogenomics, health behaviour and functional foods

# PARALLEL SESSIONS IV & V & VI

## Schutterszaal

### Session IV-A

Studying Genetic Testing: Can social scientists influence EU Policy?
*Michael Hopkins*

Sibylle Gaisser
Modelling the arena - actors and processes in genetic testing development
Michael Hopkins
The impact of DNA patenting on the development of diagnostics and their clinical application
Christien Enzing
Co-developing of a European research agenda on genomics for health services

interactive agenda session

### Session V-A

Public & professional concerns

Roald Verhoeff
Finding common ground for public dialogue on cancer genomics
Anick Dubois
How to lead the implementation of pharmacogenetics (PGx) in the agenda setting?
Kate Getliffe
What Role Does Public Concern Play in Setting the Agenda in the Regulation of Genomics?

interactive agenda session

### Session VI-A

Future user perspectives

Renske Pin
Public perception of nutrigenomics - personalized nutrition and functional foods
Anneloes Roelofsen
Future users as agenda setters for ecological genomics research
Brian Wynne
Public Science and Imagined Publics: Whose Agendas Might Be at Stake?

interactive agenda session

## Commandeurzaal

### Session IV-B

Public Health Agendas

Maxine Robertson & Jacky Swan
An assessment of the UK Genetics Knowledge Parks (GKP) Initiative
Alison Metcalfe
Using personalised genetic risk information more effectively: Implications for policy and practice
Erwin van Rijswoud
Shaping the agenda in the field of genetics and public health: an interactive scenario study

interactive agenda session

### Session V-B

Autonomy & privacy

Eric Vermeulen
Autonomy reconsidered: An 'opt out procedure' according to patients' wishes
Atina Krajewska
Genetic anti-discrimination law – need for reconceptualisation?
Jessica Wright
Privileged Project - Key Findings on Public Attitudes Towards Privacy in Genetic Research

interactive agenda session

### Session VI-B

Agendas & Politics

Emma Frow
The Politics of Plants: Emerging issues for Plant Genomics and the Global Bioeconomy
Cor van de Weele
Moral agendas for genomics: how to find blind spots?
Hans Harbers
The time-politics of genomics
What about the political and policy relevance of ELSA-projects?

interactive agenda session

## Admiraalszaal

### Session IV-C

Genomics Testing & Stem Cell Research

Eric Aarden
Broadening the agenda for genomics and society; practices of provision in health care genetics
Bernhard Wieser
The contextualisation of genetic testing in reproductive care
Margaret Sleeboom-Faulkner
Tacit Collaboration in Bioethics: Human embryonic stem cell research and new biocultures in Mainland China

### Session V-C

Genomics and identity

Andrew Smart
Reviving 'Racial Medicine'? The use of race/ethnicity in genetics and biomedical research, and the implications for science and healthcare.
Liesbeth Claassen
Health threat representations and preventive behaviour in people diagnosed with Familial Hypercholesterolemia by DNA-testing
Phillis Lakeman
An offer of combined ancestry-based preconceptional carrier couple screening for cystic fibrosis and hemoglobinopathies: response in a multi-ethnic population

interactive agenda session

### Session VI-C

Genomics regulation

Dana Wilson-Kovacs
Stem Cell Research Agendas: Regulation as Culture in Practice
Arnold Roosendaal
When Patent Offices Become Ethical Committees. Human embryonic stem cell patents and morality clauses.
Moxuan Li
To See the World in a Grain of Rice: Contesting the Commercialisation of GM Rice in China

## Compagnieszaal

### Session IV-D

The role of trust in the public acceptance of genomics
*Christine Critchley, Elizabeth Hardie & Renske Pin*

Christine Critchley
Commercializing controversial research: What are the consequences for public trust?
Elizabeth Hardie
Community responses to a hypothetical scenario involving genetic profiling for health promotion purposes: trust and other reasons for behavioural intentions.
Renske Pin
The role of trust in public perception of personalized nutrition: A comparison of Australia and The Netherlands

### Session V-D

New perspectives on moral education in genomics

*Arend Jan Waarlo*

Jenny Lewis
Classroom discussion of socio-scientific issues. The role of genomics knowledge
Paul van der Zande
Dealing with controversial genomics issues in the classroom. Mapping teachers' expertise and students' informal reasoning
Dirk Jan Boerwinkel
New strategies for moral education in genomics

### Session VI-D

Anything new?

Barbara Prainsack
The Emperor's Old Clothes: Examining the 'bio' in 'sociality'
Joanna Goven
Shaping the ELSA agenda: new technologies and old politics
Peter Stegmaier
Doing Society and Genomics

## Anti-chambre Admiraal

### Session IV-E

Genomics education through imagination

*Nicolien Wieringa*

Nicolien Wieringa
Qualitative analysis of a science theatre play about nutrigenomics, food technology and lifestyles
Flo Ticehurst
Boy Genius: Exploring Genetics through Interactive Theatre for Young People
Frans Meulenberg
Education through fiction. The effects of images, icons and ideas on moral reasoning about genomics

### Session V-E

Sharing expertise: ELSA genomics from research to boardroom?
*Erwin van Rijswoud, Hub Zwart & Hedwig te Molder*

Robert Evans
Rethinking Expertise: What's in it for ELSA genomics researchers?
Alan Irwin
Response to Robert Evans
Pierre-Benoit Joly
Response to Robert Evans
Hedwig te Molder
Response to Robert Evans
Erwin van Rijswoud
Response to Robert Evans

### Session VI-E

International declarations on bioethics: an assessment "from within"
*Hub Zwart*

Ruth Chadwick
Statements by the HUGO ethics committee: a reflection
Mairi Levitt
Globalising bioethics: a case study (1)
Hub Zwart
Globalising bioethics: a case study (2)
Darryl Macer
Response to presentations

## Anti-chambre Compagnie

### Session IV-F

Genomics knowledge and the Self

Marko Silvestric
Breast cancer as boundary object – Impacts of genetic research on clinical practice
Floris Tomasini
Trustworthiness, personalised nutrition and nutrigenomics
Joëlle Vailly
Expanding abnormality: neonatal screening, prenatal diagnosis and cystic fibrosis in France

### Session V-F

Genomics discourse

Martin Döring
Constructing the Metabolic Syndrome: The Scientific Aetiology of a Disease Concept
Wouter de Groot
The artificial body: an empirical exploration of lay ethics
Rixt Komduur
Prevention and Nutrigenomics: An analysis of talk on genetics, overweight and health risks

SETTING THE AGENDA

# Genomics & Society

Amsterdam, 17 & 18 April 2008

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Understanding and improving the interaction between society and genomics, that is the mission of the Centre for Society and Genomics (CSG), based at the Radboud University in Nijmegen. CSG is one of the Genomics Centres of the Netherlands Genomics Initiative (NGI). 'Genomics' is a young but rapidly growing field of science with far-reaching impact on healthcare, food, industry and the environment. Since 2004, CSG has developed a coherent programme on genomics and society, which includes interdisciplinary research as well as innovative communication and education activities.

CSG research projects are carried out at many universities in the Netherlands and include a variety of disciplines (e.g. philosophy, sociology, STS, ethics and social psychology). All projects combine research with innovative methods of societal interaction and foster collaboration with genomics scientists, policy-makers and stakeholders.

**About the ESRC Genomics Network**
The ESRC Genomics Network is a multi-million investment by the UK's Economic and Social Research Council (ESRC), dedicated to examining the development and use of the science and technologies of genomics.

The EGN spans five of the UK's leading universities, and involves over a hundred researchers, from professors to PhD students, as well as an international cast of visiting research fellows. It is one of the largest social science investments in the ESRC's current portfolio, and is growing into the largest concentration of social scientific research on genomics in the world.

The activities of the EGN span the whole field of genomics, covering areas as diverse as plant and animal genetics, embryonic stem cell research, and associated health applications.

The EGN includes CESAgen (Lancaster University and Cardiff University), Egenis (Exeter University), Innogen (University of Edinburgh and the Open University) and Genomics Forum (Edinburgh).

# FOREWORD

**Dear delegates,**

Welcome to the fifth international conference on society and genomics, organised by the Centre for Society and Genomics (CSG) and the ESRC Genomics Network (United Kingdom). We hope you will have a pleasant stay in our capital, Amsterdam, and a stimulating and productive dialogue with colleagues from different parts of the world.

The number of research projects dedicated to the societal aspect of genomics is still growing. Indicative for this growth is the fact that both the Centre for Society and Genomics and the ESRC Genomics Network have recently been awarded a new period of funding (2008- 2012). Also, elsewhere in Europe we see new initiatives arise. It is a challenge for all of us to make ELSA genomics – and perhaps more broadly, ELSA life-sciences – an indispensable part of both the sciences and the agendas of those who need to deal with or decide about the applications of genomics science and technology.

The theme of this year's conference is 'Genomics and Society: Setting the Agenda'. We aim not only to study or discuss the agenda of genomics science and technology, we also aim to shape this agenda in an interactive way. To do so, we have invited a series of individuals involved in setting and/or implementing genomics agendas. These individuals will act as commentator in specific 'panels' and are coming from the fields of science, policy, and professional practices. We hope this interactive element will enrich the experience of our conference.

A lot of people have been working behind the scenes to make this conference possible. I would like to thank the programme committee and the staff of both the Centre for Society and Genomics and the Centre for the Economic and Social Aspects of Genomics (CESAGen) for their time and effort.

I wish you all a good conference,

Annemiek Nelis
General Director CSG

# CONFERENCE ORGANISING COMMITTEE

**Organising Committee**
Maria Cantore (Conference Secretariat)
Frans van Dam (Communication)
Gijs van der Starre (Management)
Hub Zwart (Coordination)

**Programme committee**
Hub Zwart (chair), CSG
Annemiek Nelis, CSG
Maud Radstake, CSG
Frans van Dam, CSG
Richard Tutton, CESAGen, Lancaster / EGN Network

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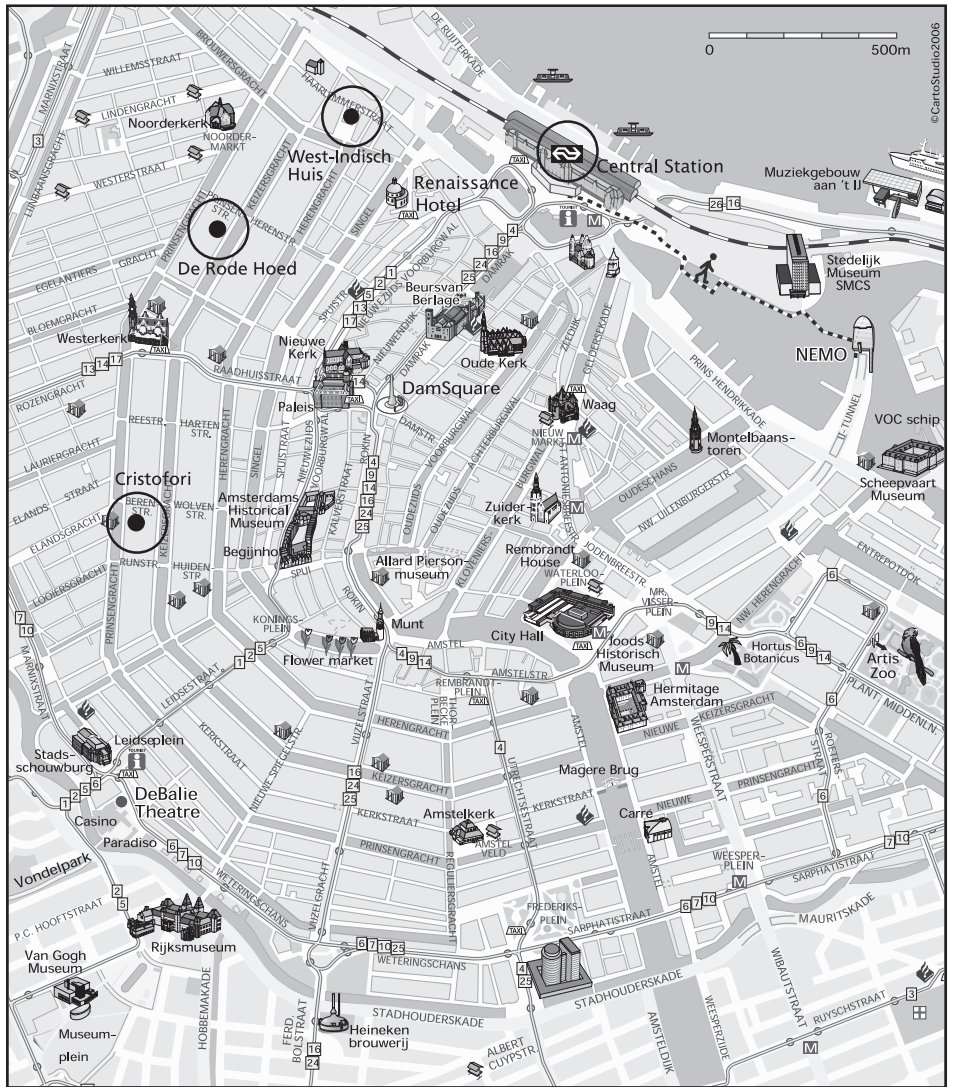
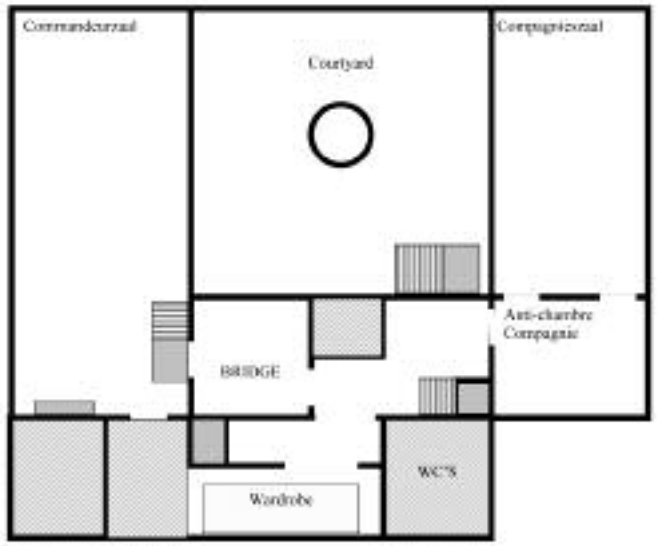
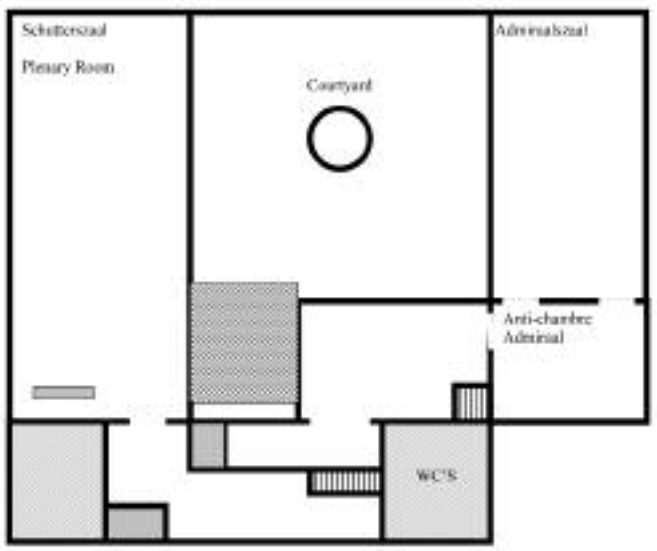
# MAP OF CENTRAL AMSTERDAM



Ground Floor




First Floor

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West-Indisch Huis
Herenmarkt 99
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## Wednesday, 16 April, 20.30

**'The Human Project', Pandemonia science theatre**
*Venue* **De Rode Hoed**

'The Human Project' is a fast-paced satirical soap set in the gene age.
Ronnie is a hot-shot party organiser, Ottoline a bright young lawyer. From the moment they meet, it's love at first sight. They're the perfect couple. And soon they're dreaming of the perfect marriage and the perfect family. But Ottoline's mother is unhappy with the match. She insists that Ronnie take a DNA test, and pass it! Before long the gene-age lovers get tangled up in a DNA drama and discover things about each other that perhaps they didn't want to know.

Since 1988 Pandemonia has been devising and producing science theatre. Plays, sketches and performances which bring science to life, and make it accessible for a broad public. Theatre to stimulate curiosity and excite a sense of wonder about the universe around us. Theatre which questions the role of science in society. Dramatic, humorous, innovative, informative and most important - interactive.

Pandemonia has a core company of six people - writers, designers, directors and business team. The plays are performed by freelance actors. With over 900 performances Pandemonia reaches on average 80,000 people a year, of which 70% is under 18.

*artistic director* Tony Maples
*business director* Lea Witmondt
www.pandemonia.nl

**How to get there?**
From the central railway station it is a 15 minutes walk. You can also reach de Rode Hoed by streetcar. From Centraal Station, take line 1, 2, 5, 13 en 17 and get off at 'Nieuwezijds Kolk'. Using lines 13 or 17 you can also get off at 'Westermarkt'.
See the Map of central Amsterdam on page 7.

**Address**
De Rode Hoed
Keizersgracht 102
1015 CV Amsterdam
Tel: + 31 (0)20-638 56 06

## Thursday 17 – Friday 18 April

*Conference venue* **West-Indisch Huis**

The conference takes place in the West-Indisch Huis in central Amsterdam, close to the central railway station.

The West-Indisch Huis is the former headquarters of the West-Indische Compagnie (WIC) in Amsterdam. From this building, the commanders of WIC ordered to build a fortress on the Isle of Manhattan in 1625, which was the start of New York.

**How to get there?**

The West-Indisch Huis is within walking distance (10 minutes) from the central railway station station. See the Map of central Amsterdam on page 7.

**Address**

West-Indisch Huis
Herenmarkt 99
1013 EC Amsterdam
tel: + 31 (0)20 625 75 28

## Thursday 17 April

*Conference dinner* **Cristofori**

In this magnificent, monumental building, situated along the Prinsengracht, CSG and the EGN Network will host the conference dinner.

**How to get there?**

From the central railway station, you can take various southbound streetcars. Take e.g. nrs 1 or 5 and get off at 'Spui (Nieuwezijds Voorburgwal)'. From there it is a seven minutes walk to Cristofori. See the Map of central Amsterdam on page 7.

**Address**

Prinsengracht 581-583
1016 HT Amsterdam
+ 31 (0) 20 63 82 679 / 679



# PLENARY PROGRAMME

## PLENARY 1 - THURSDAY, 17 APRIL 2008

**Opening**
**Annemiek Nelis, general director CSG**

Annemiek Nelis is general director of the Centre for Society and Genomics (CSG) and researcher in the field of the sociology of science and technology (STS). Her research projects focus on the role of patient organisations in the development of new genetic technnologies and on normative questions in research practices. Her research is financed by NWO and ZON-MW. Annemiek Nelis received her PhD in 1998. Her thesis deals with the development of clinical genetics and DNA-diagnostics in the Netherlands. After receiving her PhD she became a research fellow at the Anglia Polytechnic University in Cambridge (UK). She has also worked as a lecturer at the Vrije Universiteit (VU) and the University of Amsterdam.

**'Governance and ethics in genomics in the EU: reflection on interaction between experts, policy-makers and the society'**
**Pēteris Zilgalvis**

Pēteris Zilgalvis (Latvia, 1964) is Head of the Governance and Ethics Unit, Directorate Science, Economy and Society at DG Research, European Commission, Brussels. Until 2005, he was deputy head of the Bioethics Department of the Council of Europe. In addition he has held various positions in the Latvian civil service and at the World Bank in Moscow and Riga.

Dr. Zilgalvis studied political sciences (cum laude) at the University of California, Los Angeles. At the Law Center of the University of Southern California he obtained his JD (Doctor of Jurisprudence). He has published over 25 publications on bioethics, economic reform and environmental law in English and in Latvian.

Genomics research produces knowledge, artifacts and services that raise ethical, legal and social issues. Many of such issues are international in their impact, thus meriting discussion and action on an international and/or European level. The 'ELSA genomics' field is however relatively fragmented and ranging widely across diverse disciplines, which limits its impact on the European policy level.

Research and its impacts in general have become highly international. Reflecting that development, a central element of European research policy is the establishment of a European Research Area (ERA); an `internal market` for research where researchers, technology and knowledge circulate freely. The European Commission supports adherence to high standards of governance and ethics in the ERA in numerous ways. It places emphasis on exchanging best practises on ethics between Member States, on broader, upstream involvement of civil society organizations in research activities and on supporting multidisciplinary research.

**'Forensic genomics and interaction with policy-makers'**
**Peter de Knijff**

Peter de Knijff is author and co-author of over 150 articles and book chapters on various genetic research topics. His main scientific interests are the development and use of polymorphic markers on the human Y chromosome, the interpretation of forensic DNA evidence, and fundamental population genetic and evolutionary genetics. Current research projects are aimed at (i) the reconstruction of the phylogeography of closely related Avian-taxa, (ii) the genetic mapping of a language border among human populations in the Himalayan mountain range, (iii) the genetic identification of population substructures in The Netherlands, and (iv) initiating archaeoepidemiological research by means of ancient DNA studies. Since 1994 he is the head of the Forensic Laboratory for DNA Research of Leiden University Medical Center (FLDO - LUMC). He is the director of the recently initiated NGI Forensic Genomics Research consortium which represents the strategic alliance of the three important Dutch forensic genetic research laboratories: the Netherlands Forensic Institute (NFI), the Department for Forensic Molecular Biology of the Erasmus Medical Center, (FMB-EMC), and FLDO - LUMC.

**Summary**

It will soon be possible to reliably reconstruct a genetic ancestry profile and/or a visible external characteristics profile of many hitherto unknown suspects of crime. This will be entirely due to the rapidly growing array of genomic research tools, and it seems that there is very little that will stop these fascinating technological developments. For some this will seem like a nightmare, for others it will be a dream come true. In many countries there is intense debate about the possible implementation of these advanced forensics genetic research tools. However, in The Netherlands we already have a legal basis for the routine use of these tests and, unless the current political climate suddenly change drastically, we will very soon see the first actual criminal cases presented in court based on these advanced tests.

Two recently published highly influential papers (see below) clearly warn against the routine use of genetic ancestry profiling (or ethnicity testing). Yet, such warning almost seem naïve and far too late if one browses through the long list of companies already offering genetic ancestry testing for the general public. One could argue that if the general public has already massively embraced such a test, is it realistic to assume that it can be stopped in its forensic application? I will try to argue that there still is a valuable role for policy-makers and ethicists in still ongoing and future debates about such tests, but only if they are willing to adopt a different strategy. I will illustrate this by means of some of my own current forensic genomic research dilemmas.





**'Genohype, metaphors and direct engagement with the manipulation of life'**
**Oron Catts**

Oron Catts (1967) Artist, researcher and curator. Co-Founder and Director of SymbioticA, School of Anatomy & Human Biology, University of Western Australia. SymbioticA is an artistic laboratory dedicated to the research, learning and critique of the life sciences and enables artists to engage in wet biology practices in biological laboratories. SymbioticA was awarded the inaugural Prix Ars Electronica Golden Nica in Hybrid Art (2007) Catts exhibited and presented his and SymbioticA's work internationally including NY MoMA, Ars Electronica, National Gallery of Vitoria, Tate Modern and elsewhere. He was a research fellow at Harvard Medical School, and is now working with the EMA program at Stanford University on an art and biology initiative.

The mainstream discourse regarding the life sciences in the popular media, social sciences, the arts and even to a certain extent within the biological sciences seems to focus on genetics and molecular biology, even when the processes discussed have little or nothing to do with that level of biological intervention. This talk does not set out to underestimate the advances in molecular knowledge but is rather a critique of the DNA mania (Denis Noble) or Genohype (Neil Holtzman). Furthermore, looking at life under the constraint of metaphors associated with the Genome may lead to misunderstandings of the mechanisms of life and certainly will limit the potential for different understandings that are not compatible with the molecular view of life.
The problem is that much of what is happening in biomedical research and application does not so neatly adhere to the "life as genetics" approach. The origin of the developments and the conceptual framework that brought, for example, regenerative medicine about are often neglected and ignored. As a result the debates tend to use the same frame of mind and the same metaphors concerning genetic manipulation to deal with other forms of biological engagement. This presentation will demonstrate the importance of direct engagement with the life science through research in order to develop a more nuanced, pluralistic, and informed discourse.

**'The globalisation and internationalisation of ELSA genomics and bioethics'**
**Darryl Macer**

Darryl R.J. Macer is Regional Advisor on Social and Human Sciences in Asia and the Pacific, in RUSHSAP, UNESCO Bangkok, Thailand. He is also an Affiliated Professor in Bioethics at United Nations University Institute of Advanced Studies since 2002; and Founding Director, Eubios Ethics Institute, Japan, New Zealand and Thailand (http://eubios.info/index.htm), since 1990. He taught bioethics at the University of Tsukuba, Japan from 1990-2005. Born in 1962 in Christchurch, New Zealand, he has a B.Sc (Hons) in Biochemistry from Lincoln College, University of Canterbury, 1983; Ph.D. in Biochemistry at the MRC Laboratory of Molecular Biology, and Trinity College, University of Cambridge, U.K., 1987. He has since worked in

UK, New Zealand, Italy, Japan and Thailand.
He is member of the International Union of Biological Sciences (IUBS) Bioethics Committee, HUGO Ethics Committee and Secretary of Asian Bioethics Association. He is a former member of UNESCO International Bioethics Committee and a Board Member of International Association of Bioethics. He is Editor, Eubios Journal of Asian and International Bioethics since 1990, and has published 8 authored books, 20 edited books, and 180+ academic papers. Books include a Cross Cultural Introduction to Bioethics, Bioethics is Love of Life, Bioethics for the People by the People.

**Summary**
There have been debates in almost every corner of the globe over the ethical issues of genomics and gradual increase in the internationalization of the issues being discussed. Despite the unanimous acceptance of international declarations relating to ethics of genomics and human rights in UNESCO, and related international instruments by other UN agencies, there are gaps in the implementation of these standards into national laws and guidelines in many countries. This paper will discuss the situation relating to implementation of such standards, and the accompanying debates, in particular in the Asia and Pacific region. Strategies to better implement these standards will be compared, along with identification of the gaps between needs of different sectors of the communities in countries at a range of different socio-economic levels. Gaps in the framework of international ethical guidelines will be analyzed with suggestions for further policy documents from HUGO, other professional organizations, and international bodies. Areas which may be better dealt with at the national level will also be identified.

**'Conclusions'**
**George Gaskell, London School of Economics**
George Gaskell studied psychology at University College London and is currently professor of Social Psychology and director of the Methodology Institute at the London School of Economics (LSE). At LSE, he is also Associate Director of the BIOS Research Centre for the study of Bioscience, Biomedicine, Biotechnology and Society and involved in the Social Psychology Institute. Gaskell is Vice Chair of the Advisory Committee on Science and Society in the 6th Framework Programme European Commission. On behalf of DG Research of the European Commission, he chairs the Expert Group on Social Values, Science and Technology. He is a member of the international advisory board of the Program in Applied Ethics and Biotechnology at the University of Toronto Joint Centre for Bioethics and of the European Federation of Biotechnology, Task Group on Public Perceptions of Biotechnology. His particular research interests are expert and lay representations of risk, societal impacts of genomics and science, technology and the public, as well as economic psychology, trust, attitudes and social representations. In his field of interest, George Gaskell published numerous scientific articles, books, book chapters and reports.





During the conference, a number of researchers will be presenting a poster about their research projects (see page 98-106). The posters that are on display during the conference will participate in a poster-competition. This competition is comprised of two separate parts: one prize by the audience and one by a selected jury. The jury is composed of Arend-Jan Waarlo, Mairi Levitt, Hub Zwart and David Wield.

**Delegate's prize**
Upon registration, each conference delegate will obtain one marble with which he or she can give a vote to one of the posters. Near each poster you will find a tube to put in the marble to articulate your vote. The poster that has received the largest number of marbles is the winner of the delegates-competition. If more posters obtain the same number of marbles, the prize will be split between the authors of these posters. Make sure you vote in the morning or afternoon of the first day of the conference (April 17th), as the marbles will be counted later that day, at 18.00 hours.

**Jury's prize**
The jury will review the posters on the basis of the following criteria:
1. How clear is the text?
2. How clear is the point that the author wants to make?
3. In what way is this point presented?
4. How original or innovative is this poster?

**Procedure**
It is possible that both the conference delegates and the jury nominate the same poster. In this case there will be only one winner.

The winner(s) of the poster competition will be made public during the dinner on Thursday evening the 17th of April. The winner(s) will receive an Amazon book voucher.

**The Organising Committee**

# SESSION I-A

# ELSA GENOMICS RESEARCH IN PSYCHIATRY: RESULTS, REQUIREMENTS, AND EFFECTS

*Session organiser* I Baart

Genomics research will lead to ontological and epistemological transformations in psychiatry, and will have important implications for psychiatric interventions, clinical practice, and the psychiatric subject (and subjects in general). In this session results from ELSA genomics research in this domain will be presented. At the same time two questions will be addressed: 1. are there specific theoretical and methodological requirements for ELSA genomics research in the psychiatric domain, and: 2: should or can results of the ELSA genomics research feed back into psychiatric practice and under what conditions?

A psychiatrist involved in genomics research will be asked to comment on the three papers presented.

*Author(s)* I Baart
*Institution(s)* Department of Medical Humanities, VU Medical Centre, Amsterdam, NL
*Title* From deep truths to wide networks: toward new ontologies and epistemologies in psychiatry

Genomics-research contributes to important ontological and epistemological changes in psychiatry. On the one hand molecularization starts to connect neuroses and psychoses, on the other hand, diseases are fragmenting into 'dimensions' and 'symptoms'. Also the strict demarcation between 'normal' and 'abnormal' starts shifting. Paradoxically, the origin of psychiatric illnesses will not be constructed as a 'deep inner truth' anymore, but as the result of a network of susceptibility and co-acting factors.
Three lines of development will be presented, based on literature study and interviews with stakeholders involved in two Dutch large scale and long-term psychiatric research-projects.

1. Modernization and the rise of genomics research
   'Modernization' of the psychiatric research-process results in large research-consortiums and thus stimulates complex genomics research.
2. Endophenotypes
   Endophenotype research will probably not succeed in revealing 'deep' genetic truths, but will create 'wide' networks by relating molecular, neurobiological, psychological, and somatic components.
3. Gene-environment interactions
   Despite the agreement that genes operate in conjunction with environments, researchers differ in their conceptualisation of this interaction, with different consequences. There is a growing tendency that social environments will re-enter the psychiatric stage, via the backdoor of genomics because they will be integrated as into the new networks of co-acting components.

Consequences for psychiatric interventions and the psychiatric subject of these developments will be discussed; life technologies and an ethic of self-control will emerge.



*Author(s)* V Rabeharisoa
*Institution(s)* Centre de Sociologie de l'Innovation, Ecole de Mines de Paris, France
*Title* Towards a new form of medical work in psychiatry genetics: the case of autism

My presentation will draw on ethnographic observations of a series of medical consultations and staffs, which gather child psychiatrists and pediatric-geneticists. Their objective is to take over the diagnostic work for adolescents and young adults who had been diagnosed with "autism" in their childhood.
I will demonstrate that an original medical work is taking shape here, which I call a "clinical medicine of mutations". It consists in inquiring about the patient's body troubles, whose psychiatric versus organic origins are not easy to pin down, and in questioning the articulation between biomedical entities with an ambiguous status, and syndromes which are unstable to a greater or lesser degree. My contention is that this form of medical investigation stands as far from genetic reductionism, as from "bio-psycho-social" relativism.
I will then show that child psychiatrists and pediatric-geneticists are thus forced to reflect upon investigations that should be planned to highlight each patient's situation, as well as on the very nature of their judgment and medical decision. I will argue that it is not the objectivity of the judgment and the decision, strictly speaking, which is at stake, but their reliability and their robustness.
I will conclude my presentation with a discussion of the forms of objectivity in clinical work within biomedicine.

*Author(s)* S Ootes
*Institution(s)* Department of General Practice, Section Medical Ethics, AMC / Universiteit van Amsterdam, NL
*Title* Psychiatric dis-orders: about genetic causes & social problems

Genetic definitions of psychiatry portray psychiatric disorders as diseases of the body. In this paper I will make use of the methodological toolbox of Myriam Winance to suggest a different way of analysing what psychiatric problems 'are'. In her research Winance studies disability and shows it to be a category produced in the interaction between people and things. I will transport her analysis of socio-materiality to the field of psychiatry. Following Winance I shall look at the daily lives of psychiatric patients, to examine what kind of problems psychiatric patients are actually facing.
Hereby, I will suggest that the genetic definition of psychiatric problems can be analysed as one particular ordering of socio-materiality among others, hunting for causes of psychiatric disorders in the body. An ethnographic description of psychiatric practice situates the problems psychiatric patients are dealing with in their daily lives instead. To tackle these problems it does not matter what the causes of psychiatric problems are, but how we can shape socio-materiality in a way that accommodates differences between people. Genetics, with its inclination to concentrate on diseases and causes does not bring us many tools for that.

SESSION I-B

# EMBRYONIC STEM CELL RESEARCH: AN ANALYSIS OF THE LEGAL POSITIONS DEVELOPED IN THE UK, BELGIUM, AND GERMANY

*Session organiser* J Deckers

Legal debate on embryo research was reignited in the last few years of the second millennium, when cloning techniques and techniques to develop stem cells from embryos were developed. This debate produced new legislation on embryo research in many countries. Many countries have followed in the footsteps of the UK, the first state to permit the use of cloning techniques and embryonic stem cell research, yet not all have adopted the 'liberal' stance adopted in the UK. The varying legal approaches adopted, range from establishing broad provision for both the creation and the use of human embryos for research to a strict prohibition of the use of embryos. The different arguments that have been used in this debate need to be understood and clarified to answer the question if embryonic stem cell research survives ethical scrutiny. The three presenters in this thematic session have gathered expertise in discussing the arguments that have been used in Belgium, Germany, and the UK. Jan Deckers will provide a critical analysis of UK legislation, followed by critical analyses of the legal situations in Belgium and Germany, by Bart Hansen and Christine Hauskeller respectively. The aim of the session is to contribute to the development of ethical debate and policy-making on embryonic stem cell and cloning research. This will be done in two ways. Firstly, the various arguments which have been used in this debate will be exposed and evaluated. Secondly, the ways in which these policy debates have been conducted will be examined and suggestions will be made on how debates might be improved.


*Author(s)* J Deckers
*Institution(s)* Institute of Health and Society, The Medical School, Newcastle University, Newcastle-upon-Tyne, UK


*Title* UK Parliamentary debate on embryo research: what were the arguments, and how could the debate be improved?

Advances in stem cell research at the close of the twentieth century renewed debate on embryo research. In UK Parliament, the question was asked if embryo research should be extended to include embryonic stem cell research and research into the development of therapies that might result from somatic cell nuclear transfer techniques. This led to the Human Fertilisation and Embryology (Research Purposes) Regulations 2001. The first aim of my paper is to analyse and evaluate the views on the status of the human embryo that were expressed by policy–makers and –advisors in the UK debate. The second aim of my paper is to examine the style of this debate. With regard to the first aim, the question must be asked if the arguments presented in support of embryonic stem cell research survive ethical scrutiny. Are the arguments to deny full moral status to the early embryo convincing? With regard to the second aim, the question must be asked if the debate was conducted in an appropriate way, and how the style of this debate could be improved in future discussions on this issue. Did UK Parliament engage in a deliberative process whereby the merits and demerits of different views were clarified and debated, or did they base their decisions merely on their perceptions of popular opinion? Is there a need for a greater involvement from bioethicists or bioethics committees to improve the quality of future debate? It is my hope that this paper will develop our understanding of the 'tradition of ethical reasoning' (Hauskeller) in UK Parliament and to compare how this tradition might differ from ethical traditions in other countries to provide suggestions on how this debate could be carried forward in the future.


*Author(s)* C Hauskeller
*Institution(s)* Egenis, University of Exeter, UK


*Title* Science Policy and its effects on scientific creativity – German and Japanese innovations regarding pluripotent cells

This presentation starts from an account of the regulation of the use of early human embryos in research in Germany and its effects on German stem cell science. Having consistently maintained a strict 'no-dirty hands' policy in the rigid prohibition of destruction of embryos for research since 1990, Germany eventually allowed strictly controlled importation of embryonic stem cell lines in 2002. This has often been criticized as double morality, and was accompanied by scientific efforts at a material reconfiguration of the entity in question – the embryo – through the production of genetically modified embryos which would be stripped of the potential to implant into a womb and develop further. Conversely, German and Japanese teams in particular made efforts to re-programme adult cells into embryonic stem cells. In 2006 a research team from Japan (Takahashi and Yamanaka) reported that only 4 transcription factors were needed to induce pluripotency in mouse cells. Then, in November 2007, the same group and one American group published on the successful generation of so-called induced pluripotent stem cells (iPS) from human skin cells. I will raise the question whether this movement can be seen as an expression of, what I have been calling an 'adequate self-understanding of science'. Just as any other human activity, biomedical science is socially embedded and has to accommodate moral limitations. In the case of stem cell research this might mean to seek ways to create pluripotent stem cells in socially acceptable ways. The recent successes in making pluripotent cells without the destruction of embryos emerged from countries facing moral and legal objections to stem cell research and transplantation. Concerning science policy and regulation this suggests that quickly accommodating ad hoc scientific demand may not only be socio-politically problematic but can also undermine the potential for creativity in science.


*Author(s)* B Hansen
*Institution(s)* Department of Theological Ethics, Faculty of Theology, Katholieke Universiteit Leuven, Belgium


*Title* The search for ethically sound embryonic stem cells: a fool's errand?

The successful generation of so-called induced pluripotent stem cells (iPS) from human skin cells raises high expectations. The expected result of this 'embryo-saving' alternative is that embryo destruction will no longer be necessary in order to obtain stem cells, thus enabling skirting of the controversial moral and legal issues.

For several years now, the United States has outlawed the use of federal funds for research involving the creation of human embryos. Europe took a similar stance not to fund research activities intended to create human embryos solely for the purpose of research or aiming at stem cell procurement. Researchers have to tap national financial sources to create and destroy embryos for stem cell research, provided that national legislation allows that kind of research. However, most EU member states that have issued specific regulations regarding embryonic stem cell research have imposed a statutory ban on the creation of embryos merely for stem cell research.

Scientists increasingly feel impeded by these restrictions. This is shown by the recent interest in attempts to release research on embryonic stem cells from the grip of this moral and legal discussion by using subtle embryo-saving tricks e.g. clonotes, cybrids or other embryo-like artefacts.

A recurrent theme in almost all alternatives that come up for discussion is the assumption that non-viable embryos are strictly speaking no embryos at all. The argument runs as follows: non viable, therefore not an embryo, therefore not deserving of protection.

I want to argue however that this argument is an idly approach to the ethical and legal problems raised by embryonic stem cell research. They are more the result of scientific artifice and wordplay than subject to ethical sound reasoning.

Medical ethicists and lawyers should rather focus on less speculative questions raised by currently available and admissible sources of stem cells: i.e. existing embryonic stem cell lines, cord blood or other somatic tissues for which in Belgium no law currently exist.



SESSION I-C

# MOVING FROM MONOGENIC TO MULTIFACTORIAL DISORDERS: IMPLICATIONS FOR ETHICAL, LEGAL AND SOCIAL ASPECTS OF GENOMICS IN HEALTH CARE PRACTICES

*Session organiser* C van El, VU University Medical Center, Amsterdam, NL

In recent years, biomedical research has shifted from studying monogenic disorders to understanding complex gene-gene and gene-environment interactions underlying common disorders. Though association studies increasingly reveal genetic components in many common multifactorial disorders, at present it is not clear to what extent these scientific findings can be put to use in health care. Genetic testing and another tool of proven worth in monogenic disorders, taking family history, may eventually be implemented for diagnosis, disease management and prevention of some multifactorial diseases. Yet, the image of a predictive medicine envisaged at the dawn of the age of genomics is increasingly adjusted to refer to susceptibility or risk estimates. This shift has implications not only for the ways in which genomics applications may be implemented in health care, but also for the notions developed in the multidisciplinary field reflecting on this implementation, comprising studies on the ethical, legal and social aspects of genomics. For instance, notions such as psychological burden for the person being genetically tested and family members, discrimination and stigmatisation, may be less relevant when applied to multifactorial diseases.

In this session we want to explore and confront research and experiences from different disciplinary backgrounds into how genetic testing or screening could be integrated in health care practices for common multifactorial disorders in an effective and ethically and socially acceptable manner.

Author(s) D Stemerding[1] & T Swierstra[2]
Institution(s) 1 Department of Science, Technology, Health and Policy Studies, University of Twente, Enschede, NL
2 Department of Philosophy, University of Twente, Enschede, NL

Title **Genetic susceptibility testing: a new technology implying new moral controversies?**

This paper presents the results of a project in which we have developed a scenario methodology with the aim to anticipate in a systematic way possible, future patterns of interaction between technological and moral change. On the basis of this scenario methodology we have explored, as one of the case studies in our project, future practices of genetic susceptibility screening for common multi-factorial diseases. The first step in our analysis is a discussion of particular elements in the 'moral landscape' of Dutch society which have been especially important in the recent history of debates and practices of population screening, such as legally established criteria for the regulation of population screening and the constitutional right to self-determination. These elements constitute highly robust moral rules and principles which have proved their merit and may be mobilised in any debate about the

value of new forms of screening, like genetic susceptibility screening. Mobilising general rules and principles, however, always implies a translation to the specificities of a particular situation. As a result, new controversies may arise and shifts may occur in the importance and meanings attached to particular criteria and principles of screening. To what extent are such controversies and shifts to be expected in the context of emerging practices of genetic susceptibility screening? In other words, what futures can we imagine when thinking about various ways in which new options for genetic susceptibility screening might interact with established moral rules and principles in the Dutch health care landscape? In discussing this question we will focus on future options for genetic susceptibility screening of type-2 diabetes as a common multi-factorial disease.


*Author(s)* L Henneman
*Institution(s)* EMGO Institute, Dept of Public and Occupational health, VU University Medical Center, Amsterdam, NL

*Title* **Genetics and multifactorial disorders: Impact of using family history on motivation to prevent disease**

So far, genetic testing for susceptibility genes for many multifactorial diseases, such as type 2 diabetes, is not yet warranted in clinical practice. Evidence based effective tailored intervention based on genomic profile is not yet available. Family history is an important risk factor that can be used not only as a surrogate marker for genetic susceptibility, but also for behavioural factors that cluster in families. Thereby family history may be a useful tool for disease prevention in public health and preventive medicine. It is well known that the best ways to prevent most common chronic diseases (e.g. diabetes, cardiovascular disease) are a healthy diet, physical exercise and non smoking. Family history information may be used either to identify high-risk groups or as an intervention tool to tailor behavioural messages. The focus of research (in multifactorial diseases) also includes assessing the potential effectiveness on health behaviour in addition to exploring the psychological impact (seen as highly important in genetic testing for monogenetic disorders). Knowledge of the impact of familial risk assessment and family information on health-related behaviours is still very limited.
It has been argued that providing people with genetic risk information, including family history information, may stimulate preventive behaviour if a person beliefs that this can reduce the risk. However if a person assigns excessive causation to genes, he or she may either adopt a fatalistic attitude towards the risk and/or accept only medical approaches. In this presentation, the results of a randomized controlled trial, set up to assess the effectiveness of communicating familial risk of type 2 diabetes on intentions to change behaviour to reduce the risks, will be presented.




*Author(s)* J Lubinski
*Institution(s)* Genetics Department, Pomeranian Medical University Szczecin & International Hereditary Cancer Center (IHCC), Poland

*Title* **Susceptibility screening for cancer: the Polish experience**

In recent years much progress has been made in applying BRCA1 and BRCA2 testing to identify high risk groups for familial breast and ovarian cancer. Yet, BRCA1/2 and a few other genes are responsible for a few per cent of breast cancer cases in the population. In 2004 professor Jan Lubinski and his team identified a gene set that allows for the identification of 70 per cent of potential cancer cases for the Polish population. Professor Lubinski is asked to reflect on his experience in translating scientific findings to set up cancer susceptibility testing and screening in Poland, and to discuss the reactions from health care professionals, policy and the public.

## SESSION I-D

# DIGITAL ELSA GENOMICS: METHOD OR MADNESS?

*Session organiser* R McNally, CESAGen Sociomics Core Facility, Lancaster University, UK

**What is the place of digital research in ELSA genomics?**
ELSI (USA) and ELSA (EU) genomics research was originally funded through a proportion of the budget allocated to study the human genome. The Centre for Society and Genomics (CSG) in the Netherlands and the UK ESRC Genomics Network continue this 'tradition' of research with ELSA agendas that include non-human genomics and related biosciences – although not everyone would classify their own research as ELSA.

This session responds to the CSG research question: 'What should research into the ethical, legal and social aspects of genomics look like in the future?' Its focus is 'digital genomics' and its counterpart in the social sciences and humanities, 'digital ELSA genomics'.

Genomics is dependent upon and mediated through digital tools and databases and cyber infrastructures. Participation/enrolment in (and exclusion from) global bioknowledge economies is in part constructed and limited by access, use and control of digital resources and computer and information technologies.

ELSA genomics researchers have not only begun to investigate these phenomena empirically, but also to go digital themselves, a phenomenon that is part of what CESAGen refers to as 'sociomics'. This includes using digital tools and databases and cyber infrastructures to study ethical, legal, social and political aspects of digital genomics and related biosciences. This is what is meant by 'digital ELSA genomics'. Digital ELSA genomics uses the internet and digital tools to analyse the use of the internet and digital tools by genomics researchers, companies, governments, the military, NGOs, other publics, and, importantly, by ELSA genomics researchers themselves.

But should, or indeed must, ELSA 'follow the genomics actors' and go digital too?

And how does digitalisation change the epistemic practices, research agendas, knowledges and communities of genomics and of ELSA genomics?

*Author(s)* R Rogers
*Institution(s)* University of Amsterdam, NL
Govcom.org Foundation, Amsterdam, NL
*Title* The Web as Resource, Source and Object of Study

The Web was once considered a space apart, a virtual realm very much separate from the real. Nowadays, the Web is considered to be integrated into everyday life – host to a 'recommendation culture' where sources on the Web and in other media are increasingly recommended not on the basis of expert input, but according to what some have called the 'wisdom of the crowd'. The Web has novel, specific answers to the questions: 'What is the value of information and which sources are to be trusted?



The talk will explore, philosophically and practically: the Web as resource, including the demise of directories the former and the impact of engines; the
Web spaces and technologies that have served as sources, e.g., the blogosphere as well as the wikiscanner; and the Web as an object of study, where the questions remain classic, does the Web have particular media effects, and what is the quality of the Web in comparison to other media? I explore how the methods may change, slightly or more radically, to take into account the specificities of the new media.

*Author(s)* M den Besten, R Schroeder & A Thomas
*Institution(s)* Oxford e-Research Centre and Oxford Internet Institute, Oxford, UK
*Title* Caught between epistemic practices and technological affordances: The story of Swiss Bio Grid

Swiss Bio Grid (SBG) is an initiative that was launched in 2004 to assess whether Grid computing technologies could be successfully deployed within the life science research community in Switzerland.
Based on interviews with project researchers, we highlight a wider feature of the life sciences: Rather than becoming integrated around a shared computational infrastructure, we see the promulgation of countless heterogeneous resources. While much of the development of the Grid has been geared towards applications in particle physics, the requirements of computational biology have been poorly supported by existing Grid solutions, and it is unlikely that this picture will change unless there is a concerted effort in adapting Grid tools and putting them on a permanent footing.

Wider conclusions can be drawn as well: the experience of SBG highlights that there is an interplay between the epistemic practices of scientific fields and the technological affordances of the tools that support these fields. In this interplay, it could well be that the practices are more resilient. That is, e-science can only be incorporated in so far as it affords the practices dominant in the field. Digitization or not, the life sciences will not turn into big science overnight, and nor will other sciences – including social sciences.

*Author(s)* B Wynne & P Oldham
*Institution(s)* ESRC CESAGen, Lancaster University, UK
*Title* Patentomics: Mapping the Intellectual Property Landscape for Synthetic Biology

Intellectual property is a prominent focus of debates within synthetic biology. Key questions focus on the potential stifling effects of multiple overlapping property claims in this emerging field, the possibility of 'open source' alternatives, and the significance of the patenting of synthetic life. However, approaches to these questions commonly focus on individual case studies rather than the wider historical and quantitative context. This paper presents the results of research to map the patent landscape for synthetic biology using large scale analytical tools, and ranges in scope from individual researchers to enabling technologies and major companies. This evidence-based approach can be characterised as 'patentomics' and

provides a range of new tools to enhance analytical capacity in the social sciences for intellectual property.

*Discussant* M Radstake, Centre for Society & Genomics, Faculty of Science, Radboud University Nijmegen, NL



# SESSION I-E
# ETHICAL, SAFETY AND SECURITY ASPECTS OF SYNTHETIC BIOLOGY

*Session organiser* A Kelle

This session will address three crucial societal dimensions of an emerging discipline in the life sciences, i.e. synthetic biology (Synbio). The three papers on the ethical, safety, and security aspects of Synbio will be based on work undertaken in the context of the EU funded project SYNBIOSAFE (see www.synbiosafe.eu), in which all authors of the three papers participate.

*Author(s)* A Deplazes[1], A Ganguli-Mitra[2], N Biller-Andorno[2]
*Institution(s)* 1 URPP (University Research Priority Programme) Ethics, University of Zürich, Switzerland
2 Centre for Ethics, Institute of Biomedical Ethics, University of Zürich, Switzerland

*Title* Ethical implications of Synthetic Biology

Today's pluralistic societies comprise a wide spectrum of lifestyles, beliefs, values and are, as a result often characterized by different-and sometimes conflicting- ethical positions. A novel technology that aims to "create life", reprogram living organisms in the manner of computers and eventually aspires to apply such "synthetic organisms" in our daily life, inevitably challenges many aspects of our value systems and viewpoints. Thus synthetic biology raises questions such as: Are these techniques going too far in the instrumentalisation of organisms, do they ignore an intrinsic value of living organisms, do they expose other human beings to unjustifiable risks? Within the Synbiosafe project we are setting up a list of ethical issues that may arise in the ethical debate and public discourse related to synthetic biology. Furthermore, we performed interviews with scientists involved in synthetic biology in order to understand how they assess the possible ethical implications of their work. We will present the preliminary results of our fact-finding process and discuss some of the ethical aspects in more detail.

*Author(s)* M Schmidt
*Institution(s)* Institute for International Dialogue and Conflict Management (IDC), Vienna, Austria

*Title* The Biosafety of Synthetic Biology

This paper will address the unintended potential negative effects that synthetic biology could create for health, agriculture or the environment. How could these biosafety issues be classified? Following from this the issue of whether synthetic biology requires a risk assessment that is different from the one used in traditional genetic engineering (recombinant DNA) will be discussed. Some applications in synthetic biology (e.g. bioremediation) could require deliberate release to the environment. Under what circumstances could such a deliberate release take place? Would such a release of novel "synthetic" organisms require a new biosafety framework? On a more fundamental level, the emergence of synthetic biology raises the question of whether new means of enhancing biosafety measures that go

beyond a mere physical containment are possible with synthetic biology. If so, which form could such measures take? Last, but not least different perceptions between the US, Europe and other parts of the world in relation to biosafety issues of synthetic biology will be addressed with a view to the possibility of forming a consensus for addressing such concerns.

*Author(s)* A Kelle
*Institution(s)* Department of European Studies and Modern Languages, University of Bath, UK & IDC, Vienna, Austria
*Title* Biosecurity Implications of Synthetic Biology – Between Awareness Raising and Policy Formulation

An appreciation of the biosecurity implications of synthetic biology – be it in the form of the resurrection of extinct viruses like the 1918 flu virus or through the creation of new organisms that could be misused as biological warfare agents – is only slowly gaining ground. Whereas parts of the US biosecurity discourse have opened up to include Synbio developments into a broadened understanding of the biological threat spectrum, no such development is discernible in Europe. The paper will therefore first present a status report on the level of biosecurity awareness among European synthetic biology practitioners. Following from this, it will map out some ideas for raising awareness in the Synbio community of the biosecurity implications of their work. It will also provide some suggestions on how this community might get involved in the developing biosecurity discourse, so as to contribute to preventing the misuse of its achievements for hostile purposes, while at the same time safeguarding as great a degree of freedom as possible for legitimate research and development activities.



# SESSION I-F
# RECONSTRUCTING GENOMICS KNOWLEDGE SYSTEMS FOR DEVELOPMENT: COUNTER POLITICS IN AGENDA SETTING?

*Session organisers* J Jongerden, CTC Wageningen University, NL & G Ruivenkamp, Athena Institute, Vrije Universiteit, Amsterdam, NL

Main concern of the participants in this session is to discuss possibilities of appropriating (the mode of) knowledge systems underlying biotechnology and genomics for the benefit of development. This session's perspective implies that it takes as a starting point i) the social shaping of technology ii) acknowledging that technology development takes place within the context of uneven and contradictory power relations and iii) investigates the possibilities of a reconstruction of technology by and for the benefit of the rural poor. Therefore, it critically reflects on the actuality of technology development (the social and material context from within technologies are constructed) and the knowledge systems underlying and mediated by them. The immediate aim is to contribute to a technology development that empowers producers and local communities in developing sustainable production and consumption systems.

*Author(s)* S Hisano
*Institution(s)* Department of Economics, Kyoto University, Japan
*Title* Actuality and Potentiality of Ethical Reflections for Reconstruction of Biotechnology

As ethical terms are becoming commonly heard in scientific research, technology development, business application and regulatory policy, it is also becoming imperative to understand the actuality of ethics that is expected to bring researchers and policy makers into critical reflections on what they are working for.

On the one hand, it is arguably true that ethical reflections can be a sort of nexus of science and society, or a discursive tool to stimulate dialogues among scientific researchers, policy makers and the public. On the other hand, however, ethics if it is applied instrumentally is often used by proponents of a certain technology to justify the application and commercialization of the technology, on the ground that, for example, GM technology enables us to produce more food with less external resources in an accessible way for rural poor in developing countries; biofuel technology enables us to produce renewable energy (and/or additional incomes by producing biofuel crops) with less CO2 emission into the environment also in an accessible way for rural poor in developing countries; genomics enables us to produce medicines more efficiently and reasonably even in a specific way for rural poor in developing countries, and so on. Such a mainstream discourse of "for the poor" or "for the environment" should be critically examined on the ground of what has actually happened at the local.

As like technology is socially constructed in the development, its applications are also socially constructed. The potentiality of technology is intertwined with the actual context of uneven and contradictory power relations. If so, ethical considerations of technology development and its applications need to be a social and political project, in which critical

social sciences should be given a space to actively commit to ethical reflections. The purpose of this paper is to go beyond the so-called ethicisation of biotechnology research by politicising biotechnology ethics. In so doing, the paper will refer to some theoretical frameworks and empirical cases concerning to hegemonic strategies and counter-hegemonic tactics.

*Author(s)* W Quaye
*Institution(s)* CTC, Social Sciences Department, Wageningen University, NL
*Title* **Reconstruction of (bio)technologies and genomics in the context of food sovereignty**

There is growing concern for more effective policies and (bio)technology/genomics development that take cognizance of local production and consumption needs in the context of food sovereignty. It has become obvious that (bio)technology/genomics development and global food availability will not ensure food security in any particular country because what is available in the world market may not necessarily be accessible by most people in the developing countries. The situation equally demands the development of community-based food (bio)technologies/genomics as food is not just a commodity to be consumed but has both social and cultural identities. Food Sovereignty concept brings to bear the need for bottom-up approach to development agenda setting where local communities and people are empowered. This paper re-emphasizes the social dynamic force of food focusing on the need for social shaping of (bio)technologies/genomics within the context of food sovereignty as an alternative to failing conventional food policies. In the presentation, a review of Food Sovereignty concept is supported with a recent local network survey conducted in Ghana. Findings from the survey reinforce the significance of food production-consumption networks as a powerful tool in building resilience to food insecurity and alleviating poverty in developing economies such as Ghana. With ever increasing cost implications and inadequate access to productive resources as well as increasing over-reliance on foreign-based industries and (bio)technologies/genomics, local communities are demanding policy space to fight against what they see as "the winner takes all syndrome" that have characterized conventional food polices. Researchers are strongly advised to consider possibilities of reconstructing knowledge systems underlying (bio)technology/genomics to reflect local network needs. Also not only should governments in developing economies be committed to promoting, defending and protecting the rights of local farmers and agricultural employees. Such policies should also consider biotechnologies/genomics related programs from food sovereignty perspective.

*Author(s)* D Puente Rodriguez
*Institution(s)* Athena Institute, Vrije Universiteit, Amsterdam, NL
CTC, Social Sciences Department, Wageningen University, NL
*Title* **Energy for the poor? Reconstructing genomics and bio-fuels regimes**

The paper addresses the session's topic by presenting a related case study. The session's aim is to discuss the existent potentialities for reconstructing genomics' knowledge systems both to empower resource-poor farmers within technological developments, and to strengthen farmers' systems themselves. This paper critically reflects on strategies exercised by local communities for commanding genomics research, and for developing local sustainable energy systems, against the background of global bio-fuel regimes.

The biotechnologization of agrarian activities has strengthened specific qualities of the historical process towards an industrialization and modernization of agriculture. One of the main features of this technological process is interchangeability of agrarian and industrial producers, products and components. This interchangeability has politicizing potentialities. For example, the world prices for agrarian products will rise not only by the growing demand in food, but also in bio-fuels. Therefore, the world market price of maize (mid-2007) is more than 50% higher than the average price between 2001 and 2005, especially, because of the use of maize for the production of ethanol. This price rising has had already dramatic consequences in Mexico where maize is staple food, and where the price of the "tortillas" (popular way to eat the maize meal) quadrupled. In this context, interchangeability has led to an absurd agrarian production system in which crops are used as energy inputs for the rich, whilst their use for feed the hungry world is neglected.

This paper, however, presents empirical evidence about how local biotech networks (Honduras, Mali and Mozambique) are linking the potentialities of genomics with the no edible oil-crop Jatropha curcas, and these with local energy production systems. In this way, the local networks gain autonomy in the production of energy without losing autonomy in the production of food. From the empirical work two conclusions are extracted. Firstly, it is suggested that interchangeability is an appropriate analytic tool not only to understand how the biotechnologization of agriculture is used by bio-industry to strengthen the industrialization and modernization process of agriculture, but also to study local sustainable developments. Secondly, it is indicated how the politicizing character of genomics might be reoriented towards local sustainable developments.

# SESSION II-A
# SPORT GENOMICS

*Author(s)* T Pieters
*Institution(s)* Metamedica, VU Medical Center, Amsterdam, NL
*Title* **Life cycles of doping products: ways of regulating genetic doping**

Doping products have been focal points of cultural enthusiasm in the public sphere as well as the locus of public contestation. The careers of drugs show a cyclical temporal course. Expanding use of doping products (amfetamines, hormones, EPO, etc.) and high expectations of their effects on their introduction are followed by rising criticism and disappointments about the benefit/risk balance. The interplay between different kinds of perception and management of side effects plays a pivotal role in shaping these product life cycles. The societal embedding of new products involves not only market success, but also regulation and public acceptance. Cultural enthusiasm about benefits, and societal concern about risks and dangers are important in this respect. Periods of controversy are excellently suited to explore these dynamics.

The recent widely publicized epidemic of injuries and deaths due to adverse reactions of hormone products in the East Germany-period has invigorated the already fierce debates on the integrity of top-class sport and its ability to continue delivering on its promise of 'Citius, Altius, Fortius'. In this paper I will discuss how the life cycles of the classic doping products interfere with the current process of developing and regulating genetic doping.

*Author(s)* I van Hilvoorde
*Institution(s)* Vrije Universiteit Amsterdam, NL
*Title* **DNA testing and biological passports in sport; full control of the 'pre-game contest'**

In May 2006 Operación Puerto led to one of the largest doping scandals in sports history. In the clinic of the Spanish sports medic Eufemanio Fuentes, many bags of manipulated blood were found, belonging to elite athletes from a variety of sports. Following this huge doping scandal, cycling authorities proposed to impose mandatory DNA testing on professional cyclists. The use of DNA could make it easier to identify other human body material, such as blood and urine. Jacques Rogge, president of the IOC, also reflected on the possibilities of creating a DNA database in order to assemble the vital genetic facts of all top-level athletes. Rogge stated: 'Today, the riders have to give urine and blood samples. Tomorrow, this has to include DNA also. It's not very painful: a pin prick inside the cheek, a bit of hair... that's less painful than blood extraction. The data would be well-stored and protected. Tell me, what's the problem?'

In this paper I will discuss some of the empirical and ethical implications of such a proposal. Empirical complexities include the organization of a DNA database, in particular concerning the question of how and when the athletes (of the future) are to be identified. The installation of such a DNA database could give rise to new strategic behaviour, for example an increasing secrecy in nurturing young athletes. Moral issues include the danger of violating privacy, the protection of DNA against other uses, an increasing criminalizing of athletes, and questions concerning consent and autonomy. The attempts made by sport authorities may be understood as the next step to improve the lack of credibility and to diminish the growing cynicism of the public at large about the supposed 'cleanness' of elite sport. These proposals meant to create transparency and credibility, may however create more suspicion and result in a situation in which athletes are 'guilty until proven innocent'.



Author(s): A Müller
Institution(s): Department Health, Ethics & Society, Maastricht University, NL
Title: **Ethical Aspects of the therapeutical application of gene technology in sports**

While the technological progress seems to make the application of (medical) know-how possible – of which (at least in the past) we thought it to be mere fiction or an unreachable utopia – a number of ethicists, especially in the body-related sciences (like medical sciences and sport sciences) become on the one hand increasingly concerned about the (promised) positive outcome of this technology. But on the other hand the concerns expressed do often appear as unjustified generalisations about biotechnology at large and gene technology in particular.

In this paper I would like to suggest that at least two aspects should be taken into consideration: a) that besides enhancement and selection – which is often referred to as creating Frankenstein's Monster – there is the other side of this technology, i.e. the preventive and therapeutic use of gene technology. And b) the highly valuable theoretical and abstract approaches should be supplemented by empirical investigations (e.g. interviews, field observations). It seems that these two aspects are more or less overlooked in the ongoing ethical discussion and especially in its criticism about the use of biotechnology in the field of sports – may it be the somehow conservative perspective or the language-analytical view. Anyway, if we regard the therapeutical use of genetic technology in some way as defensible, we should be aware that there are in all probability ethical conflicts ahead. A reflection on these ethical clashes, which can be seen in the literature as well as within the interview responses, finalises this paper.

## SESSION II-B

# IN THE BANK? CRITICAL REFLECTIONS ON THE PAST PROMISES AND FUTURE EXPECTATIONS OF BIOBANKS

*Session organiser* R Tutton

The history of biobanks has in many ways epitomized the promises and pitfalls of the 'biotechnology revolution'. At the beginning of the millennium expectations were high that biobanks would deliver new revenue streams to national economies from the exploitation of genetic and medical resources and produce scientific breakthroughs in the form of new therapeutics and diagnostics. However, several high profile biobank initiatives suffered various setbacks sometimes amidst intense controversy about their legal and governance frameworks. Scepticism also remains amongst the scientific community about the value of current biobank research design. Against this background a number of the national biobanks are now progressing or already have progressed to the phase where they are collecting and storing samples and data, including UK Biobank, Generation Scotland, Estonian Genome Project and Japan Biobank.

This is therefore an appropriate moment to look both to the past and the future to examine some central issues of sociological and legal interest in relation to biobanks. These reflect both ongoing debates and those that have taken renewed significance as biobanks move towards their data collection phase. The papers in this session will discuss a number of issues including the changing expectations about biobanks over time, scientific concerns about statistical validity of current biobank designs, normative assumptions about altruism and solidarity in relation to volunteer participation in biobanks, and the design and function of public consultations and engagement.


Author(s) R Tutton
*Institution(s)* CESAGen, Lancaster University, UK

*Title* **Banking Expectations: The Promises and Problems of Biobanks**

In the last decade governments, medical charities, pharmaceutical companies and disease advocacy organizations have spent considerable time and money developing biobanks to aid drug discovery and the investigation of disease. Drawing on work in the sociology of expectations, my paper identifies and assesses the various expectations that have driven the investment in different types of biobanks. Following the analysis of Nightingale and Martin (2004), I suggest that biobanks have been the focus of unrealistic promises about producing a 'biobank revolution' that will transform biomedicine and healthcare. My conclusion is that we need more modest expectations about what can be achieved, and that we need to tackle certain conceptual and methodological challenges for biobanks to fulfil their potential.




*Author(s)* M Bhardwaj
*Institution(s)* CESAGen, Cardiff University, UK

*Title* **Gene-environment interactions and statistical validity: ethical concerns for biobanking**

Biobanks attracted a lot of attention across the world due to their claim to provide optional treatments and future advice in health care for common but complex disorders. Complex disorders are not only polygenic, but also influenced by gene-environment interactions. As much as there remain confusions about structure and function of gene, the lack of appropriate definition of 'environment' has only added more to the uncertainties to the debate on gene-environment studies. Any scientific research is considered credible if it can be statistically validated and reproduced, and its applications are used in health care. Applications of biobanks are projected both at individual and public health level, and its implications have been argued well in ethics debates at both levels. However, of all the debates around biobanks, ethical issues of statistical validation have attracted less attention. There are methodological, analytical and political issues related to the use of statistics for validation and this paper intends to raise some of these issues particularly with regards to biobanking.


*Author(s)* M Garcia-Sancho
*Institution(s)* Centre for the History of Science, University of Manchester, UK

*Title* **Towards a long history of sequencing: the practice of data gathering and the emergence of the first protein and DNA structural databases (1965-1985)**

My paper will present sequencing as the result of a long history of interacting practices rather than a technique exclusively linked to DNA, the genomics revolution and the Human Genome Project (HGP). It will challenge the growing popular and contemporary STS literature, which engulfs the history of sequencing in that of molecular biology, considering its development a consequence of recombinant DNA and the new late 1970s and 80s biosciences. Sequencing, I will argue, emerged in the context of biochemical analysis of proteins during the 1940s, much before the origins of molecular biology and the discovery of the double helix of DNA. In its development, it interacted with practices – or ways of knowing and working – of engineering, computing and the business world before them being recasted in bioengineering, bioinformatics and biotechnology.
This long and inclusive history of sequencing will be shown by analysing the emergence of the first post-World War II biological databases. The practice of repetitively compiling data through the computer already existed in the 1950s and was associated to public and business office administration, fields far away from biology. In the 1960s, it began being applied to the storage and classification of protein sequences, but it was not until the 1980s – with the emergence of the first DNA sequence databases – that this endeavour was raised to the category of cutting-edge science, in the context of the HGP and genomics.

The incorporation of the database technology accentuated a tension already existing in sequencing between a way of work linked to repetitive application of methods and one involving innovative experimentation. This and the multiplicity of practices with which

sequencing interacted suggest that its long history does not square with the traditional categories of science, technology and interdisciplinarity, neither with the traditional boundaries between disciplines, or between academic and applied research.



# SESSION II-C
# EXPANDING NEONATAL SCREENING: CHALLENGES FOR POLICY MAKING

*Session organiser* C van El, VU University Medical Center, Amsterdam, NL

In many countries for several decades neonatal screening for genetic disorders has become a routine practice. Newborns are screened for conditions such as phenylketonuria (PKU) where early diagnosis may prevent irreversible damage. Recently, new techniques, such as tandem mass spectrometry, have allowed for a dramatic expansion of screening tests, including tests for disorders that are less treatable or untreatable. Many countries are in the process of expanding their newborn screening programmes. The possible combination of treatable and untreatable disorders in screening programmes raises important issues: informed consent versus mandatory participation, safeguarding uptake, informing and counselling parents, educating health care professionals, and last but not least securing an informed policy process involving the public. This session shows how several countries respond to some of these issues and discusses challenges for policy making.

*Author(s)* D Freitag, B Wieser, S Karner & W Berger
*Institution(s)* IFZ: Inter-University Research Centre for Technology, Work and Culture, Graz, Austria
*Title* The politics of neonatal screening.

According to the WHO guidelines neonatal screening may be mandatory. However, especially for disorders where treatment options are not as straightforward as they are for PKU, screening may be offered, but only on a voluntary basis. Austria has, however, decided to carry out neonatal screening in the framework of its mandatory reproductive care programme. The Austrian neonatal screening programme comprises testing for 23 genetic disorders.

In our paper we will especially address the style of policy making by which the Austrian neonatal care has been designed, implemented and now expanded. Initially the programme was introduced in the 1970s in a rather paternalistic style of health care policy making. This framework is shaping the professional practice in neonatal care to this day. Neonatal screening therefore stands in a sharp contrast to the way in which genetic disorders are otherwise dealt with. Parents whose children are identified with a genetic disorder are recruited in a mandatory framework for the first screening, but in the follow-up process they are transferred into a medical setting that operates according to the principles of informed consent. We will address the specific difficulties that occur if these two different medical frameworks come together and discuss implications for future policy making in neonatal care.

*Author(s)* AM Plass, L Krijgsman, L Gieling, C van El, T Pieters & M Cornel
*Institution(s)* VU University Medical Center, Amsterdam, NL
*Title* Treatable and untreatable diseases in the neonatal-screening programme: the opinion of future parents in the Netherlands.

In the Netherlands, in 2007, the neonatal screening programme was expanded from 3 to 17 disorders for which screening met the Wilson and Jungner criteria, especially regarding

treatability. In our research we investigated the opinion of future parents concerning screening newborns also for less treatable or untreatable disorders. A questionnaire was posted on the web site of a national pregnancy fair and was filled out by 1,372 prospective parents. In contrast to current policy, overall they showed a positive attitude towards inclusion of less treatable [88%] or non-treatable disorders [73%] within the national newborns screening programme. The most important reason mentioned was: to be spared a long diagnostic quest. Obtaining information to enable reproductive choices in future pregnancies was hardly mentioned.
Since a relevant part of the Dutch population seems interested in considering screening newborns for untreatable disorders we argue that further debate is needed between policy, public and health care professionals to discuss pros and cons.

*Author(s)* A Lloyd, E Parsons & A Clarke
*Institution(s)* Cardiff University, UK
*Title* **Duchenne Muscular Dystrophy and reproductive decision-making: implications of newborn screening.**

Duchenne muscular dystrophy (DMD) is an X-linked recessive disorder with an incidence of about 1:4000 live male births. The condition is characterized by progressive muscle weakness. Most affected boys become confined to a wheelchair between 8 and 12 years and life expectancy is between 15 and 30 years.
In 1990 a newborn screening programme for DMD was introduced in Wales with the aim of avoiding prolonged diagnosis, providing families with reproductive choice in subsequent pregnancies, enabling families to plan for the future and identifying a presymptomatic cohort who may benefit from future treatments. In the rest of the UK diagnosis of DMD is based on clinical presentation of health or developmental problems and occurs at a mean age of 4.5 years (range: 3 months to 8.5 years). The significant delay in clinical diagnosis may result in the birth of a second affected boy within the family before the diagnosis of the first.
This paper reports the findings of a study conducted to explore the experiences and reproductive decision-making of 38 families in Scotland whose affected boy has been clinically diagnosed, compared to 34 families in Wales whose child has been diagnosed through newborn screening. Both positive and negative experiences are reported.



# SESSION II-D
# SOCIETAL DIALOGUE: FROM ENGAGING CITIZENS TO SETTING AGENDAS

*Session organiser* M Radstake
ELSA is a combination of academic research and societal interaction with the objective to align developments in science and technology with societal trends and needs. Societal interaction, or dialogue, has largely been based on participatory methods developed for public engagement. The main question in a participatory mode of interaction has been how to engage citizens in the societal embedding of new technologies. When public engagement moves upstream – involving citizens in the early stages of innovation processes – it poses another question: whether research and policy agendas address relevant societal problems and issues, which often go beyond science and technology. In this session we present reflections on societal dialogue as a means for agenda-setting based on our own experiences in research and public engagement on nanotechnology and genomics.

*Author(s)* M Deblonde
*Institution(s)* University of Antwerp, Belgium
*Title* **Co-creating nano-imaginaries: some reflections on substantial and procedural results**

The research project Nanotechnologies for tomorrow's society – NanoSoc is an interdisciplinary research project that engages innovation networks – nanotechnologists, natural and social scientists, stakeholders and citizens in the region of Flanders, Belgium - to discuss and influence future nanotech developments in three particular fields of nanotechnology development: smart environment, bio-on-chip and new materials. The first phase of this project, which is based on the Delphi-methodology, aims at exploring possible futures via the concerted creation of nano-imaginaries. Our analysis of this Delphi-exercise provides us with some interesting observations. To start with, we cannot detect systematic differences between the substantial inputs of the three types of participants, namely nano-researchers, societal experts and interested citizens. Second, we notice some gaps between 'official' arguments in favour of nano-research and those of the participants. Third, we observe some general differences between the problems and issues discussed in the three cases. And, finally, we argue that the concerted creation of nano-imaginaries has procedural relevance, even though the substantial inputs of the three groups of participants do not differ systematically. These observations can serve as a starting point to discuss preconditions for –engagement that is successful in terms of socially robust agenda-setting.

*Author(s)* A Plows
*Institution(s)* CESAGen, Cardiff University, UK
*Title* **Upstream engagement at the grassroots: reframing the debating stakes**

Ethnographic "snapshots" such as those taken during the CESAGen Emerging Politics project 2003-2006 can provide input for "upstream public engagement". An ethnographic approach defines public engagement practices, aims and outcomes not merely as a policy tool for use in specific technical applications. Different publics frame issues in their own

terms at the grassroots in multiple social spaces, e.g. in online discussions or through the European Social Forum. "Upstream engagement" methods identify larger societal concerns framed through a 'genomics lens'. For example, specific "single issues" such as biobanks, catalyse broader debating stakes. In contributing to the development of participatory forms of deliberative democracy, it is necessary to go 'beyond pro and anti' in social debates on genomics issues. Meta-themes such as political economy, social justice, health strategies, citizenship, and identity, for example, are ways of framing more nuanced and mature social debates, with the potential to inform the political agenda.


*Author(s)* M Radstake
*Institution(s)* Centre for Society & Genomics, Faculty of Science, Radboud University Nijmegen, NL

*Title* Interactive agenda-setting through dialogue: lessons from The DNA-Dialogues

The DNA-Dialogues are online and real-life encounters between citizens and genomics researchers, initiated by the Dutch Centre for Society and Genomics (CSG). In this paper I show how the premises for The DNA-Dialogues have changed over the course of a pilot study in 2006-2007. In the initial set-up, the CSG would function as an intermediary between researchers and current real-life or online communities of citizens. If an organisation expressed interest in participating in The DNA-Dialogues after having received a general notice containing a list of possible topics, the CSG invited relevant researchers to participate.

Over the course of the pilot, however, the role of the CSG changed. First, the general notice generated little response. Genomics apparently was not considered appealing nor urgent enough. The CSG became actively involved in the articulation of issues and their implied publics, which were then related to developments in genomics. Secondly, scientists as well as citizens tended towards a mode of interaction with the experts providing information and the citizens asking questions. Most experts did not see any direct interest for their own research. Dialogue, however, requires mutual interest. Therefore the focus shifted to the transformation of professional, research and policy agendas. With that shift the professional participants, rather than the citizens, became the primary object for evaluation.



# SESSION II-E
# DYNAMICS OF GENOMICS INNOVATIONS AND THE ROLE OF USERS

*Session organiser* E Moors

Genomics is an emerging technological field, being characterized by flexibility and high uncertainties about potential technological options, applications, demand and related ethical, legal and social aspects. These aspects become articulated by interactions between involved stakeholders and the expectations each of them has. This session highlights the dynamics of emerging genomics innovations and its articulation by users (e.g. food consumers, patients and patient organisations), by focussing on the following themes:

- Classification of types of user-producer interaction, especially in emerging nutrigenomics developments. **R Nahuis & E Moors**
- Difficulty to widely adopt a number of genomic technologies in the clinic, despite high expectations that new scientific knowledge can be rapidly translated from 'bench to bedside'? **P Martin**
- Organisation of demand articulation processes in emerging genomics technologies with(in) patient groups? **W Boon**

By focussing on the role of users, this session highlights various aspects of the co-construction process between genomics technology and society, thereby addressing issues which could shape the agenda of future genomics research. The first paper develops a framework for studying user-producer interaction, while the second and third paper illustrate the variety of user involvement in shaping genomics technologies, ranging from individual patients to patient organisations.


*Author(s)* R Nahuis, E Moors & R Smits
*Institution(s)* Innovation Studies Group, Department of Innovation and Environmental Studies, Utrecht University, NL

*Title* User producer interaction in context? The case of functional food innovation

Science, Technology and Innovation Studies show that intensified user producer interaction (UPI) increases chances for successful innovations. This paper identifies and classifies types of user producer interaction, such as demand articulation, interactive learning, and domestication. It proposes a classification based on three dimensions - the phase of technology development, the flexibility of the technology, and the heterogeneity of demand - and proceeds with delineating eight different kinds of cases that each demand a different set of UPI types.

In its empirical part, the paper focuses on UPI in different phases of technology development by analysing two cases from the field of functional foods – a category of products in which the main contribution of nutrigenomics is expected. Demand articulation and enriching appear to be important UPI types in the early phase and configuring the user is important later on. The main conditions in an early phase are adequate user producer linkages and in a later phase articulated demands and trust.

*Author(s)* P Martin
*Institution(s)* Institute for Science and Society, University of Nottingham, UK
*Title* User-producer links and the socio-technical shaping of novel therapeutics

This paper will consider why a number of important novel biological therapies are having difficulty being successfully adopted in the clinic. Data from pharmacogenetics, haematopoietic stem cells and tissue engineering case studies will be used to illustrate a number of points: a) that establishing clinical utility (CU) is key to determining the success or failure of a novel technology; b) that CU has to be understood in multi-dimensional terms that relate to the embeddedness of medical practice in complex socio-technical regimes; c) that successful therapeutic technologies are socially shaped during clinical development to embody key aspects of CU. As a consequence, different forms of medical knowledge need to be drawn on during their specification, design, and testing, which requires active collaboration with clinical end users. In conclusion, ideas from STS, medical sociology and organisational studies will be drawn on to outline a more robust framework for understanding the dynamics of clinical adoption and the key role of users in medical innovation.

*Author(s)* W Boon
*Institution(s)* Innovation Studies Group, Department of Innovation and Environmental Studies, Copernicus Institute, Utrecht University, NL
*Title* Demand articulation in emerging genomics technologies: the role of patient organisations

Emerging technologies are characterised by high levels of uncertainty, expectations and "fluidity". This means that it is important for stakeholders to bring forward their demands (problems, needs, ideas, etc.) and in this way be involved in shaping the technology and its societal embedding. In the field of pharmacogenomics innovations, patient organisations play a role in these demand articulation processes. Therefore, we focus on the question whether and how demand articulation and related social learning processes are organised within and with patient groups? And to what extent the positioning by other stakeholders agrees with the self-positioning of these patient groups? We do this by using the event history analysis methodology to analyse two patient organisations ('Dutch Breast Cancer Organisation' and 'Dutch Muscular Disease Association') and compare them.



# SESSION II-F
# SHARING THE BENEFITS OF GENOMICS WITH DEVELOPING COUNTRIES

*Session organisers* W Vroom & B de Jonge

This session deals with the potential benefits of genomics research in the context of international agricultural development. Contemporary global genomics development is characterised by a 'genomics divide', which calls for a more equal access to the benefits of genomics technologies for the global south. Such a 'sharing the benefits of genomics' first of all needs to address potentially restrictive intellectual property regimes that limit the extent to which genomics innovations can be accessed and used in developing countries. But while big commercial interests are at stake in protecting genomics innovations, at the same time humanitarian licensing, Corporate Social Responsibility (CSR) and public-private partnership have become interesting and important elements in the international activities of public sector institutes, and multinational biotechnology companies. This session will explore what the potential is of these trends in terms of sharing the benefits of genomics research, and what the limits to these approaches are.

In addition, international public sector programmes focus on bridging the currently existing 'genomics divide'. But in spite of the good intentions, such initiatives are at the centre of tensions between top-down international agricultural development, and the need for bottom-up priority setting and empowering local innovation systems. The question is how upstream innovation systems can be linked with downstream informal seed systems in developing countries. Only if such questions of interlinking innovation systems are addressed, can we really start to explore the sharing of benefits of genomics with developing countries.

In terms of setting the agenda of genomics research and policy, the themes addressed in this session have important implications for intellectual property policies of public sector institutes, the public debate on the role of multinational biotech companies in international agricultural development, and the way in which upstream genomics research can be organized to have a relevant impact in farmers' fields in developing countries.

*Author(s)* B de Jonge
*Institution(s)* Applied Philosophy, Wageningen University, NL
*Title* Sharing the Benefits of the Potato: From Peru to the Netherlands and Back Again?

Since the rise of the life sciences, questions about the sharing of plant genetic resources and the benefits derived from their use have entered the international policy arena. In this article, I will reflect on the many issues and viewpoints related to these questions in respect to the potato in an era of plant genomics. It will appear that different groups have very different opinions about the rights and duty's they and others have concerning the sharing of the benefits of this important crop. Yet, all these different perspectives are closely related and can only be explained in connection to each other. In this way, the article will shed some light on the position Dutch genomics research centre's have in these interrelations and

reflect on their policies with respect to Intellectual Property and Benefit-Sharing. Thereby, the outcomes of the international workshop "Sharing the Benefits of Genomics & Biotechnologies Research:
Reconsidering Intellectual Property Policies in public research" will be presented and reflected upon. This workshop can be considered a case in practice with regard to the question to what extent ELSA genomics research feeds into or shapes the agendas of genomics research, policy practices and public debate.


*Author(s)* K Papageorgiou
*Institution(s)* University of California, Irvine, US

*Title* Genomics Research and Agricultural Development: A View from the Nile

The international policy landscape of trade agreements and intellectual property regimes that regulate genomics research oftentimes hinders its application in the developing world. My presentation focuses on the attempts of public and private sectors to bring agricultural biotechnology to the farmers in Egypt. I examine Egypt's regulatory framework and the attempts to deal with the twofold challenge presented by research in plant genomics: a) the establishment of a comprehensive intellectual property rights law that renders foodstuffs, plant species and microbiological processes patentable, and b) the formation of a biosafety protocol that secures the safe release of genetically modified organisms in the fields and the market. I trace the trajectory of Egyptian agricultural biotechnology as I observed it between 2003 and 2006 and present the country's intricate involvement in the notorious WTO case over GMOs filed by the United States against the European Commission. My paper oscillates between the national and the international, policy and science, theory and practice and addresses the delays, disappointment and confusion that characterize agricultural biotechnology in this particular locale. In so doing, my presentation tackles the existing global "genomics divide" and explores the limits and potential of the current institutional arrangements with regard to sharing the benefits of genomics research.


*Author(s)* W Vroom
*Institution(s)* Social Sciences Group, Wageningen University, NL
Athena Institute, Vrije Universiteit Amsterdam, NL

*Title* Linking upstream genomics innovation systems with informal seed systems: the case of the Generation Challenge Programme

Contemporary international genomics development is characterised by a 'genomics divide' between the global north and south, which calls for a more equal access to this technology from the global south. However, what is even more challenging is not just how to bridge this 'divide', but how to usefully link upstream genomics innovation with informal seed systems in developing countries.

CGIAR's 'Generation Challenge Programme' is aimed at "using plant genetic diversity, advanced genomic science and comparative biology to develop tools and technologies that help plant breeders in the developing world produce better crop varieties for resource-poor farmers." This programme is explicitly aimed at bridging the genomics divide, but is also committed to a bottom-up priority setting with local stakeholders. This produces a tension between delivering tangible and concrete research outputs, and allowing local innovation systems to work out in what way genomics has an added value for local crop breeding.

This paper delves into these tensions and asks the question how to reconcile donor's requirements to demonstrate impacts and delivery strategies, with a need to allow for bottom-up and demand-driven plant breeding strategies. In addressing these questions, the paper explicitly focuses on the concrete material outputs of the Generation Challenge Programme and the extent to which they mitigate the tension between top-down genomics research, and the needs that emerge in local innovation systems.

# SESSION III-A

# BEHAVIOURAL GENOMICS AND THE CASE OF ADDICTION: WHAT ABOUT AUTONOMY AND RESPONSIBILITY?

*Session organiser* J de Jong

Currently, we are witnessing a shift in the conceptualisation of addiction. Addiction is increasingly conceptualised as a chronic brain disease with a neurobiological and genetic basis. Behavioural genomics contributes to this conceptual change. Research into the genetics and neurobiology of addiction suggests that long-term abuse of alcohol or drugs causes changes in the structure and the functioning of the human brain (neuroadaptation). In order to describe the impact of these changes often the metaphor of the 'hijacked brain' is used: the hijackers (alcohol or drugs) are taking over control and determine behaviour. The current brain disease model of addiction (including the hijacking metaphor) raises questions concerning individual autonomy and responsibility. If the addict is subjected to factors that are beyond his/her control, does (s)he still have a free will? Or is the addict's individual autonomy and responsibility fundamentally undermined? In this session, the relation between behavioural genomics, addiction, individual autonomy and responsibility is explored.

*Author(s)* R Holdsworth
*Institution(s)* Egenis, University of Exeter, UK

*Title* **Behavioural genomics: the case for a multidisciplinary interpretation**

Recent advances in research into the human and other genomes have provided new data for the various scientific disciplines engaged in the study of the origins of human behaviour. These disciplines range from the long-established, such as behavioural genetics, to the comparatively new, such as human evolutionary genetics and biomolecular archaeology. How large the set of such disciplines is thought to be depends, admittedly, on how we define 'behaviour' and its 'origins'. However, research conducted by the author has shown that the set is potentially much larger than might at first sight be expected. This research has been a philosophical enquiry, examining the assumptions, concepts, theories and methods of a number of disciplines, eight of which were the subject of semi-structured interviews with research practitioners. This paper will explain the method adopted in this research, summarise the conclusions and make the case for a multidisciplinary interpretation of 'behavioural genomics'.

*Author(s)* B van de Wetering
*Institution(s)* BoumanGGZ, Rotterdam, NL

*Title* **Addiction as a brain disease: policy and practical implications**

This presentation places the genomics of addiction in a broader (historical) perspective and focuses on the question whether the brain disease model will or should replace the traditional moral model of addiction. Is the traditional model inadequate because it adheres to outdated views of free will and responsibility? Is it correct to claim that the brain disease model has taken over? Can we speak of a paradigmatic shift? Or should we recognise that both models contain some truth depending on what aspect of addiction is stressed? And what are the implications for policy and practice when addiction is seen as a brain disease?

*Author(s)* T Walker
*Institution(s)* Centre for Professional Ethics, Keele, UK

*Title* **The implications of the brain disease model for ascriptions of responsibility to addicts**

This paper considers two accounts of what we might be interested in when considering the responsibility of addicts. On the one hand, we might be concerned with an addict's responsibility for her actions while addicted (for example, her actions in obtaining and using the drug she is addicted to). On the other, we may be concerned with an addict's responsibility for her condition (for example, her responsibility for becoming, or remaining, addicted). The two are connected – even if we hold that an addict is not autonomous when using drugs, and hence would not normally be responsible for doing so, we might still hold her responsible if she is responsible for putting herself in a position where her autonomy is compromised in this way. The hijacking metaphor seems to apply most readily, if it applies at all, to the first of these concerns. Here, however, the focus will be on the second type of concern, and will explore the implications of the brain disease model (particularly with a genetic component) for ascriptions of responsibility to addicts of this type.

*Author(s)* J de Jong
*Institution(s)* Department Health, Ethics & Society, Maastricht University, Maastricht, NL

*Title* **Addiction and autonomy: normative implications of the brain disease model**

The brain disease model with its hijacking metaphor raises important normative questions on how addicts should be treated and cared for. The central question in this presentation is whether the neurobiology of addiction should change our normative framework regarding practices of pressure and coercion in treating addicts. In the current framework concerning the provision of care and treatment for addicts the principles of individual autonomy and responsibility are central. But should these principles still hold true for addicts, in particular for the severely, long-term addicted persons whose decision making capacities (according to the brain disease model) are said to be fundamentally undermined? And what are the consequences if these principles are abandoned? How will or should this change the practice of treatment and care for (all) addicts? Will the use of pressure and coercion become more easily justified? Will it perhaps lead to a more humane treatment of addicts? These questions will be addressed in the presentation.

## SESSION III-B

# GOVERNANCE, PUBLICS AND BIOBANKS

*Session organiser* R Tutton

*Author(s)* N Kanellopoulou
*Institution(s)* ESRC Genomics Forum /AHRC Research Centre for Studies in IP & Technology Law, Edinburgh, UK
*Title* **Normative Assumptions in Genomic Banking: Solidarity, Equity and Reciprocity**

This paper examines existing principles in the establishment of biobanks for research and persistent paradoxes in their regulation. Considerations of social responsibility and moral obligation in research participation are counter-balanced by 'key control dilemmas'; due to the increased value of human tissue and diverse understandings of our relationship with our body, it may not be sustainable much longer for regulators to maintain that people do not see value in 'their' bodies, do not retain an interest in how samples and data are used or their fate after use. This paper critically discusses prevailing normative assumptions about altruism and solidarity in current governance frameworks for biobanking projects. It proposes the re-interpretation of human genomic sharedness through notions of reciprocity. This study is part of new research on legal models of empowerment in genomics research participation, which places the role of the law in broader social and ethical context.

*Author(s)* G Haddow & S Cunningham-Burley
*Institution(s)* INNOGEN, University of Edinburgh, UK
*Title* **Deliberation and representation: diverse purposes and practices in exploring views about genetic databases**

Generation Scotland covers three different genetic databases for epidemiological and clinically related genetic studies. A programme of public consultation and engagement has run alongside these scientific programmes, from inception to implementation. This has enabled us to explore different perceptions and expectations across diverse groups and to promote the utilization of such results within the research protocols. In this paper we shall draw specifically on the qualitative and quantitative work related directly to the Scottish Family Health Study, one part of Generation Scotland. The deliberative, qualitative work involved a small group of active citizens and raised concerns about access, use/abuse, confidentiality and anonymity. These issues then informed the content of a survey of a representative sample of the adult population in Scotland which, among other things, looked at willingness to participate. We compare the results of these different methods and what this means for engagement and consultation and the recommendations for practice that can be made from diverse and even divergent results.

*Author(s)* C Heeney[1] & F Milanovic[2]
*Institution(s)* 1 Ethox Centre, Oxford University, UK
2 INSERM, Toulouse University, France
*Title* **Biobanks and Public Health: A comparison between the relationships of biobanks to the public health systems in the UK and France?**

Our paper focuses on the 'embeddedness' of the biobanks in the public health systems in the UK and France respectively. We discuss the differences between biobanks in the two countries using their formal and informal governance and funding arrangements to provide insight into their relationship with the public health system. We consider the policy context for these initiatives with particular emphasis on how they envisage the sharing of data and samples between biobanks and public health organisations. We employ data collected as part of 2 sociological studies, one in France and one in the UK, which have focused on the governance of biobanks and similar initiatives. We will take 4 biobanking initiatives, 2 from the UK and 2 from France. We examine how their collections are generated and accessed. We will critically employ Actor Network Theory as a theoretical basis for analysis and comparison of our empirical data.

The paper draws on data and policy literature for two types of biobanking initiatives, disease specific (namely cancer) and prospective studies (looking at the genetic basis for common complex disorders), in relation to public health systems in France and the UK respectively. Our empirical data provides insight into the practices of biobanks and researchers in the public health system. By examining the formal and informal governance arrangements for the biobanks we explore how they facilitate direct or indirect interaction with the public health systems. We will look at the flow of data and samples between the health systems and the biobanks and the position of scientists, clinicians and researchers in relation to this. The paper draws some preliminary conclusions about what would constitute a mutually beneficial relationship between the biobanks and public health and how the case studies we have looked at fit into this model.

# SESSION III-C
# GENETIC TESTING

*Author(s)* A Brüninghaus
*Institution(s)* FSP BIOGUM/ FG Medizin, University of Hamburg, Germany
*Title* **Self-Perception and Decision-Making in Predictive Genetic Testing - an Explanatory Model for Individual Decisions Making in Genetic Testing**

Postnatal predictive genetic testing enables identifying hereditary disease dispositions, promising a chance for preventive measures in a number of cases. However, the outcome of genetic testing can also induce negative psychological and social consequences. Research in the context of genetic counselling has therefore examined the understanding of test results by the clients (medical-psychological perspective), and the biographical consequences of genetic counselling and testing for the individual client (psychic-social perspective).
In addition to this, this paper introduces a process-oriented perspective, focusing on the process of forming the decision pro or contra genetic testing that consists of a sequence of interdependent micro-decisions. The 'black box' that hides changes in the client's (self-)perception is examined using narratives that expose individual motivations and justifications for steps in the decision process. The interpretation of this development as a process of individual development and learning (German: "Bildung") highlights how being confronted with the possibility of genetic prediction affects the individual's identity.
From the analysis of this individual development, the influence of determining factors on the decision making process can be demonstrated. Knowing when and how changes in the client's (self-)perception occur allows to construct an explanatory model of the process of individual decision making. It has the potential to connect the client's point of view to professional practice in the field of genetics, to improve genetic counselling and to adapt it even better to the individual needs.

*Author(s)* J Gupta
*Institution(s)* International Institute for Asian Studies, Leiden University, NL
*Title* **Genetic testing and pregnant women's choices in India**

Genetic problems associated with reproduction – either during pregnancy, or leading to infertility and recurrent foetal loss - are the commonest indications for genetic testing and counselling in India. At the abstract level, traditional ideas regarding (causes of) health and illness, and at the practical level, availability, accessibility and affordability of services, are seen to affect uptake of the existing technology.

The overt and covert pressure faced by Indian women from the family and society regarding the number and sex of their children is well-known. Lesser known are the pressures on women to give birth to a `healthy' child. While the financial burden of caring for an affected child and the lack of institutional facilities for care of the disabled are important factors, most women/couples also fear the stigma the birth of a 'disabled' child may bring. Little attention has been given to unequal gender relations and the role of the family in decision making regarding testing. Women are often blamed by others and also blame themselves and feel a sense of guilt and shame for producing a child with a handicap or genetic disease. The pressure on women to undergo tests and to opt for abortion in case an anomaly is detected is high. Evidence indicates that women's choices are highly circumscribed. The choices of pregnant women/couples are rarely individual; rather they are embedded in constellations of the patriarchal family, kinship and community.

Based on empirical research in genetic clinics in Delhi, I conclude that pregnant women are being jettisoned into the role of autonomous and responsible decision-makers regarding genetic testing whereas the information which they possess is highly inadequate and incomplete and their life circumstances too constraining for them to make autonomous and considered decisions. I argue for a gender-sensitive approach in genetic counselling.

*Author(s)* C Janssens[1], M Gwinn[2], C van Duijn[3] & M Khoury[2]
*Institution(s)* 1 Department of Public Health, Erasmus University Medical Center, Rotterdam, NL
2 National Office of Public Health Genomics, Centers for Disease Control and Prevention, Atlanta, USA
3 Department of Epidemiology & Biostatistics, Erasmus University Medical Center, Rotterdam, NL
*Title* **Predictive Testing for Multiple Genetic Variants in Common Diseases: A different ELSI landscape from testing for traditional genetic diseases**

Unravelling the genetic origins of multifactorial diseases is expected to lead to personalized medicine, in which prevention and treatment are based on tests for multiple genetic variants (genetic profiles). Balancing the enthusiasm for this development is concern about ethical, legal, and social implications (ELSI) of genomic medicine. These implications may not be the same as for genetic testing in monogenic disorders.
We conducted a simulation study to evaluate the predictive value and inheritance patterns of genetic profiles. We simulated genetic profiles and disease status for 1 million persons. Profiles included 40 genetic variants. Frequencies of risk genotypes varied in separate scenarios from 1% to 50% and odds ratios from 1.1 to 3.0. Population disease risk was 10%. Results were compared with genetic tests for Huntington's disease and hereditary cancers and their implications for the discourse on ethical, legal and social issues were considered.
While genetic tests for monogenic disorders typically have two outcome results (high and low risk), genetic profiling yields a continuum of possible risk estimates, with minimal risk differences between profiles. Also genetic variants decrease the risk of some diseases and at the same time increase the risk of other diseases. This enormous variation in genetic profiles and in their effects on disease risks reduces the potential for discrimination and stigmatization. Furthermore, when each variant in the profile segregates independently, the probability of inheriting the same at-risk profile is very low, implying that privacy concerns for family members (e.g., the right not to know) are less of an issue in complex diseases.
Our simulation studies show that the predictive value and inheritance of genetic profiles differ fundamentally from those of single, high-penetrance genetic variants. These differences have implications for the discourse on ethical, legal, and social issues of genetic profiling.

# SESSION III-D
# ENGAGING SCIENTISTS

*Author(s)* J Calvert
*Institution(s)* Innogen, University of Edinburgh, UK
*Title* **Contributor, collaborator or critic? The role of the social scientist in synthetic biology**

This paper reflects on my experiences of being the 'token' social scientist in emerging debates around synthetic biology in the UK. At the first synthetic biology conference I attended I was labelled a 'member of society' in the programme (social scientist = member of society). With the UK's research councils requiring social science input into new proposals in synthetic biology I was suddenly in the unusual situation of being besieged by requests from natural scientists to be part of their research proposals (social scientist = funding stream). In being asked to join a working party on synthetic biology I was asked to single-handedly represent the social, legal, philosophical and ethical perspectives (social scientist = ELSA expert). In this paper I critically reflect on these experiences. What is the role for social scientists in these contexts? Does one have to choose between being a contributor, a collaborator or a critic? What methodological and theoretical insights can be gained from experiences such as these?

*Author(s)* A van Gorp, A van der Giessen & C Enzing
*Institution(s)* TNO Quality of Life, Innovation Policy Group, Delft, NL
*Title* **Informing the public or interacting with society; the impact of societal interaction activities on genomics research**

Within the field of science communication research there is a strong emphasis on the influence of societal interaction activities on the public opinion of science. There is little or no focus on if and how these activities of researchers that provide information or that participate in public debates might influence their research. This article presents the results of an exploratory study on the impact of the societal interaction activities of genomics researchers on their research according to the genomics researchers. On the basis of a survey under 441 scientists involved in one of the Dutch genomics research centre funded by NGI data have been collected; with a response of 23%. Slightly more than half of the respondents indicate that societal interaction activities should be aimed at creating a dialogue with the public. This could mean that researchers also learn from the public during societal interaction activities. According to 60% of the respondents the societal interaction activities in which they participated have an influence on their research. A third of the respondents says that these activities provide them with new contacts. About the same number of respondents claims that science communication activities help in creating public support. A similar percentage of the respondents claims that they get new information and interesting insights that they can use during their research.
Societal interaction activities by genomics researchers might be helpful in setting the research agenda as at this moment 60 % of the genomics researchers that responded claim that participating in societal interaction activities does influence their research.



*Author(s)* B Rappert
*Institution(s)* University of Exeter, UK
*Title* **Engaging with Scientists in Matters of Controversy: A Proposed Method**

In recent years, the continuing high public profile of ethical, social, and political issues associated with scientific research has renewed attention to long standing questions about its place in society. This presentation elaborates an empirical research agenda for engaging with practicing scientists regarding the governance of their work and their individual responsibilities. Substantively, the presentation considers the links between genetics and security. Post 9-11, the relationship between national security and research has been a topic that has received considerable attention. As part of this, questions are being raised regarding whether the knowledge and techniques generated through genomics and related fields might facilitate the production of bioweapons; and therefore whether controls should be placed on what gets done, how, and whether information is widely circulated. In discussing the preparation for, the planning of and the conducting some one hundred seminars with scientists about these issues, the presentation aims to propose a strategy of engagement for other areas of emerging controversy. Various tensions and lessons are recounted with a view to considering the choices made in efforts to promote responsive life science and social research.

# SESSION III-E

# GUIDING LIFE SCIENCES GOVERNANCE IN THE AGE OF GENOMICS

*Session organiser* E Moors

Genomics is on the edge of largely changing the society. It is interesting, therefore, to study how various governance arrangements in life sciences (e.g. of industry, health professionals, patients, insurers, legislators) are changing due to genomics innovations, and how to guide future genomics developments in order to fit the innovative genomics technology to societal needs. Accordingly, this session focuses on various innovation perspectives on governance in life sciences in the age of genomics:

- The concept of appropriate risk governance in life sciences. J Tait
- The development of tools to create and sustain alignments in and around genomics innovation chains. T Propp & E Moors
- The role of regulatory pathways on life sciences innovations. A Faulkner & I Geesink
- The role of multi-stakeholder forums in governing genetic testing. F Merkx

This session aims at obtaining more insight in life sciences governance processes in the context of emerging genomics innovations, in order to take full advantage of new genomics developments in the future.

*Author(s)* J Tait
*Institution(s)* Innogen Centre, University of Edinburgh, UK

*Title* **Appropiate Risk Governance of Innovative Technology in Life Sciences**

In the governance of innovations in life sciences, risk regulation often has great difficulty in keeping pace with new fundamental discoveries with potential application in medicine and agriculture, e.g. stem cells, synthetic biology, pharmacogenetics, GM animals, new GM crop developments. Policy makers often need to make decisions more rapidly than they would like, in the absence of sufficient information about the nature of the products themselves, far less about the risks they may present. This systemic problem involves numerous interrelated issues. For example: risk-related decisions are often based on inappropriate historical precedents, exacerbating existing barriers to trade or setting up new ones; some innovative products are raising issues for which there are no regulatory precedents; and, regulators are struggling to reconcile competing demands for greater stakeholder involvement in risk-related decision making and at the same time for a more evidence-based approach to decision making. There is a need for widely accepted international guidelines on meeting these challenges without unduly impacting on commercial competitiveness and international trade, and in full recognition of the selective impact of different forms of regulation on different types of company and different industry sectors.



*Author(s)* T Propp & E Moors
*Institution(s)* Innovation Studies Group, Department of Innovation and Environmental Studies, Utrecht University, NL

*Title* **Tools for aligning genomics innovations. Expectations of convergence on pharmaco- and nutrigenomics based 'personalized health'**

Alignment of actors in different sectors with product visions based on uptake of promising new science and technology can lead to a blurring of boundaries of product categories and sector identities. Expectations create challenges for policymaking, where the benefits of new technologies and products have to be weighed against the problems of boundary transgression and the obsolescence of existing governance and regulatory arrangements. We address the policy and regulation challenges that genomics based visions of personalized healthcare present. Relevant questions are: Which areas must policy makers focus on when supporting genomics based visions? What tools must be found, which arrangements must be changed so as to support innovation? What are undesired consequences of changing arrangements? What vision seems feasible enough to be aligned with, what other visions of genomics and the future of disorder prevention and management are there? Our argument is that policy makers need to assess expectations of convergence on personalized health in the context of other expectations and activities along competing trajectories. The tool set we present combines articulation of the socio-technical contingencies of visions of genomics based products and treatments with tools for contextualization of visions within alternative, potentially competing scenarios.

*Author(s)* A Faulkner & I Geesink
*Institution(s)* Cardiff University School of Social Sciences, UK

*Title* **Technological zones and regulatory pathways: the snakes and ladders of tissue-engineered medical technology formation in the European Union**

In the late 1990s a failed attempt to introduce human tissue as a category in medical device legislation resulted in continuing patchwork of innovation-inhibiting national legislation. In the 2000s, two major pieces of EU legislation have been negotiated, one addressing safety of the sourcing, banking and processing of human materials, the other market approval procedures for products. National Health Technology Assessment and other regimes provide further steerage.

Tissue engineering (TE) may be understood currently as an unstable and weakly-bounded 'technological zone', characterised by a number of fracture lines. These include divisions between public healthcare ('users') and commercial enterprise; tissue banking and therapeutic services; medical device and pharmaceutical jurisdictions; ethics and technicality; medical device, cell therapy and pharmaceutical sectoral classifications; national and supranational innovation policy; and between tissue engineering itself and 'adjacent' zones. Given this fractured zone, the emerging EU regulation and national governance provide regulatory pathways defining rules of engagement that promote some innovation routes and inhibit others. Referring to particular types of TE products, the paper considers theoretical concepts for understanding the contrasting, zone-organising forces observed – such as coherence vs. division; flexibility vs. lock-in (and lock-out); and harmonisation vs. disjunction.

*Author(s)* F Merkx
*Institution(s)* Rathenau Institute, The Hague, NL
*Title* **The role of hybrid forums in governing the introduction of novelties: the case of genetic testing and insurance selection**

When novel technologies get introduced into society, new social role responsibilities are introduced sideways. It is clear that we can consider these shifting and emerging responsibilities. Sometimes new responsibilities are explicitly discussed and form part of the introduction trajectory of a novel technology. Such was the case with the introduction of genetic testing, where insurance companies were attributed new social responsibilities. I will argue that the governance of novel technologies should be directed at the improvement and facilitation of the processes by which configurations of responsibilities get reorganized when novel technologies are introduced into society. I will present the results of a case study on genetic testing and insurance selection and discuss what we can learn from this case about the process of organizing responsibilities. I will focus in particular on the productive role of so-called hybrid forums, deliberative settings in which a heterogeneous set of actors and heterogeneous type of arguments co-exist and co-evolve.



# SESSION III-F
# INTERACTION AND BOUNDARY CROSSING IN NUTRIGENOMICS

*Session organiser* R Vandeberg

Nutrigenomics is characterised by high uncertainty about scientific discoveries, industrial possibilities and societal desirability. For the assessment of a nutrigenomics future the involved heterogeneous stakeholders have to cross their boundaries and interact in order to set the agenda. This session pushes the limits of the boundaries both within and around nutrigenomics by addressing the following themes:

- How do research institutes interact and cross the boundaries between their respective sites, disciplines and cultures to gain insight in the molecular workings of nutrition? Bart Penders
- Is there a difference in boundary crossing and interactive learning between research institutes and industry in nutrigenomics consortia in different countries and how is this influenced? Rens Vandeberg
- What is the boundary between nutrigenomics and pharmacogenomics, between health and disease and what are the implications of a possible convergence? Sibylle Gaisser

In this session a broad scope on interaction and boundary crossing is presented. Through their diverse approaches the presenters generate a good overview of interactions between stakeholders and agenda setting in nutrigenomics. Three papers will be presented with boundary crossing as the cross-cutting theme. At the same time 'linking pins' between the papers will be articulated during the presentations in order to come to a discussion on boundary crossing in nutrigenomics on a higher aggregation level.

*Author(s)* B Penders
*Institution(s)* Department of Health, Ethics & Society, Maastricht University, NL
*Title* **Norms and Politics in Contemporary 'Big Nutrition'**

Large-scale research initiatives are not only characterized by their size, but often also by their diversity. Various institutes cooperate, resulting in a diverse patchwork blanket of disciplines, approaches, sites, experiments and boundaries. Such boundaries, traversing "Big Nutrition" cannot simply be transcended because of e.g. their material and epistemological roots. Boundaries have not vanished between industry and science, or between disciplines or styles within science, nor have they remained static, unaltered by the dynamic practice of large-scale nutrition science. Such divisions in scientific practice are of importance in understanding how problems are tackled and solutions constructed, or shorter: how is it 'made to work'. In the process of 'making it work', various elements of the research situation are locally re-made. As a result, while health was sought, healths were found and the biopolitics of large-scale nutrition science grew multidirectional. Research was made modular with respect to its work and its politics.

*Author(s)* R Vandeberg & E Moors
*Institution(s)* Department of Innovation Studies, Copernicus Institute, Utrecht University, NL
*Title* **Interactive Learning in Nutrigenomics: A Comparison between The Netherlands and Germany**

Innovation is an interactive learning process which is of special interest for emerging technologies like nutrigenomics. In nutrigenomics stakeholders have to cross their boundaries in order to combine complex complementary (tacit) knowledge for e.g. the construction of a shared vision or agenda for the nutrigenomics future. Although the importance of interactive learning is widely acknowledged, an adequate model for studying interactive learning is still missing. Contrary to most studies in the field of learning, we did not only look at the outcome but also opened the black box of the interactive learning process. We developed a model based on characteristic elements of the interactive learning process (i.e. prime mover, intermediary, network formation and knowledge flows), the influencing conditions based on the importance of face-to-face contact for tacit knowledge interchange (geographical, cognitive, regulatory, cultural and organisational proximity), and the outcome. We applied the model in two nutrigenomics consortia in The Netherlands and Germany respectively.

*Author(s)* S Gaisser, B Buehrlen & B Huesing
*Institution(s)* Fraunhofer Institute for Systems and Innovation Research, Karlsruhe, Germany
*Title* **Nutrigenomics at the interface of genetic testing, pharmacogenomics, health behaviour and functional foods**

Nutrigenomics is the study and application of knowledge on a person's genetic status in the field of nutrition. The use of genetic information originates from medicine and particularly from the detection of increased risk of disease. Prevention and early treatment build the link to nutritional factors that moderate health and well-being. Carrying a particular genetic variant, however, does not yet determine with certainty the future outbreak of the related disease. Other fields of uncertainty are the pathways linking genes, metabolome, risk factors, external influences, and nutritional ingredients with disease. These open scientific questions lead to a floating demarcation of health from illness, thus both leaving healthcare professionals, consumers and patients in concerns and opening the field for new products and services. The traditions and potentials of the actors in the field (science, pharmaceutical and food industry, healthcare professionals, regulatory agencies, consumers/patients) as well as their changing roles and interfaces will be discussed.



# SESSION IV-A
# STUDYING GENETIC TESTING: CAN SOCIAL SCIENTISTS INFLUENCE EU POLICY?

*Session organiser* M Hopkins

Social science research has a role to play in informing policy makers in areas where complex scientific, technical, social, ethical, legal and economic issues intermingle and where the claims of all actors need to be critically assessed. Collaboration between the European Commission's Joint Research Centre (JRC), especially its Institute for Prospective Technological Studies (IPTS) and the European Techno-economic Policy Support Network (ETEPS) facilitates this research. ETEPS is a network of researchers at independent public and private sector research institutions that act as a channel, to conduct and communicate the results of commissioned studies on key policy issues related to emerging technologies, such as genomics. As sponsor, IPTS has been active in this field and a number of previous studies have provided the basis for policy reports that have been widely disseminated. These include several studies related to the development and application of pharmacogenetics and other genetic technologies which have served Commission services, as well as being presented to academia, industry, and international organisations (e.g. the OECD) through publications and presentations. Past projects have had notable impacts including the establishment of the Eurogentest European network of excellence that supports genetic testing laboratories.

In this session three papers are presented that outline examples of work on genomics, both completed and underway that has been supported by IPTS, as well as the European Commission's Framework Programme 6, and the CanGeneTest Consortium surrounding. The session illustrates the role of social science in informing policy makers and offers the opportunity to disseminate results of research, as well as to incorporate feedback from an informed audience into live projects. The session draws together papers based on three IPTS studies (as well as additional research) that each have involved international reviews, comparisons, and collaboration. The first paper sets the scene by outlining the key stages in translation of genomic knowledge as well as mapping the main actor groups and their roles. The second paper provides an overview of issues surrounding the patenting of DNA and the development of diagnostics. The paper emphasises the complexity of the issues, the dynamic nature of the problem and some immediate policy implications. The third paper outlines the development of a 'vision document' for a European research agenda for the integration of genomic knowledge and technologies into health services, and will use the session as an explicit opportunity for consultation with an informed audience of academics and stakeholders.

*Author(s)* S Gaisser
*Institution(s)* Fraunhofer Institute for Systems and Innovation Research, Karlsruhe, Germany
*Title* **Modelling the arena – actors and processes in genetic testing development**

It is widely accepted that the medical product development process is no longer able to keep pace with scientific innovation. The result is a technological disconnect between discovery

and product development process, i.e. the steps involved in turning new laboratory discoveries into treatments that are safe and effective.

The presented study determined the state-of-the-art in genetic testing development, identified actors, framework conditions and processes in the development of genetic testing applications. Based on internet searches and an online survey of public research groups, the current focus of pharmacogenetic and pharmacogenomic (PGx) technology, and institutional framework conditions for its performance were determined. The main areas of PGx research are the liver, neoplasms, the cardiovascular and central nervous systems. Collaborations are important for knowledge transfer between private and public sector. From this knowledge and additional literature analysis a conceptual framework model was derived illustrating the main actors and their interaction within the context of the sectoral innovation system. Genetic testing development is mainly carried out by basic and applied researchers within the academic surrounding, hospital and service labs, the diagnostic industry and the biopharmaceutical industry. Crucial steps in the developmental pipeline are basic research, prototype design or discovery, preclinical development, clinical development, product development, filing/registration and approval, and sustained engineering. Genetic testing in the clinic is used in specific commercial test kits, in homebrew applications, and as a result of drug-diagnostic co-development in personalized medicines. During the developmental process various factors hinder the efficient knowledge and technology transfer into clinical application. The deeper understanding of the steps involved in the developmental pipeline was used as a basis for discussion with all stakeholders involved in the process. This led to a shared understanding of the process and the contribution of each role in the developmental process. The improvement of the communication process helps to develop a shared understanding of which data is required for efficient uptake of new technologies, the study methodology and who could be in charge of producing the information. This culminates in a set of measures to streamline the innovation process of genetic testing.

*Author(s)* M Hopkins
*Institution(s)* SPRU, University of Sussex, UK
*Title* **The impact of DNA patenting on the development of diagnostics and their clinical application**

Intellectual property rights (IPR) have been generally considered an important incentive for innovation as they facilitate the sharing of new knowledge (from inventions) with the scientific community and society as a whole. In parallel, they reward the inventor for disclosure of the invention with the right to exclude others from commercially exploiting the invention for a limited time. In spite of the presumed stimulating effect on innovation, patenting has on occasion been suggested to potentially inhibit research and patient access to medical technologies. A particular case is the proliferation of DNA patents, and the resulting expectation of limited access to novel treatments and diagnostics (e.g. as a result of high licensing fees). This fear is particularly supported by cases where patent holders have made broad claims or exert strict monopoly rights (e.g. Myriad Genetics holds or has licensed several patents on the breast cancer genes BRCA1 and BRCA2). There is wide concern that diagnostic testing could be inhibited by patent thickets, especially as emerging techniques allow the detection of multiple mutations at a time (microarray-based tests) to diagnose disease susceptibility or drug disposition. This paper outlines the objectives of an IPTS study underway to reduce uncertainty by systematically investigating, for the first time in Europe, possible impacts from DNA patenting in the field of diagnostics. The paper sets the scene by exploring the empirical evidence from the EU and USA provided by studies that cover a range of stakeholders. It reveals key trends in DNA patenting, the changing strategies of patent holders, the response of service providers, draws some balanced policy implications, and describes questions that are the subject of ongoing research.

*Author(s)* C Enzing
*Institution(s)* TNO Innovation Policy Group, Delft, NL
*Title* **Co-developing of a European research agenda on genomics for health services**

Given the proposition that genomics can provide an important contribution to improve health services in Europe, the question addressed in the presentation is what are the main barriers that prevent this uptake and how can research provide answers and solutions to overcome them?

Recent advances in molecular biology, genetics and genomics have shaped new opportunities for the prevention and treatment of both common and rare diseases. Emerging new technologies could facilitate the development of preventive medicine and more effective interventions. However there are several barriers that prevent a timely uptake of genomics in health practices. These barriers relate to factors and actors involved in the new genomics-related products' development process and its introduction into the health sector, including both specificities of genomics-related products such as the mode of application (e.g. safety, efficacy) and its economic evaluation (e.g. cost-benefit) and the assessment of the new product by various stakeholders (scientist, doctors, patients, industry, government, etc.).

Preliminary results of an ongoing European study are presented and discussed with the audience of policy makers, professionals, genome researchers and public organizations. The results of this discussion will contribute to focus the interviews, planned in the next phase of the project in summer 2008 with a number of stakeholders in the field.

The results of the study will be a first step towards the development of a European research agenda for the integration of genomic knowledge and technologies into health services. Additionally the study will bring together the perspectives of representatives from key stakeholder groups at the European level, co-developing a framework for better integration of genomics in health care.

# SESSION IV-B
# PUBLIC HEALTH AGENDAS

*Author(s)* M Robertson[1] & J Swan[2]
*Institution(s)* 1 Queen Mary University of London
2 University of Warwick, UK
*Title* An assessment of the UK Genetics Knowledge Parks (GKP) Initiative

The UK GKP initiative was set up in 2002. The aim was to reduce the translational gap that exists by encouraging what is referred to as 'Mode 2' forms of knowledge production (Gibbons et al, 1994) amongst academic, clinical, commercial and consumer groups (patients and 'the public') which would facilitate the translation of genetic knowledge into new clinical practices.
The Mode 1/ 2 thesis states:
'The old paradigm of scientific discovery ('Mode 1') – characterised by the hegemony of the theoretical or, at any rate, experimental science; by an internal taxonomy of disciplines, and by the autonomy of scientists and their host institutions …. was being superseded by a new paradigm of knowledge production ('mode 2') which is socially distributed, application oriented, trans-disciplinary, and subject to multiple accountabilities' (Nowotny et al, 2001, p. 179).
The GKP initiative was an explicit attempt to organize and manage 'Mode 2' knowledge production, but the management of 'Mode 2' knowledge production has largely been unexplored. Whilst the relationship between 'Mode 2' science and 'Mode 2' society has been theorised as co-evolutionary, empirical work investigating these dynamics is lacking.
Our research, which traced the development and evolution of this initiative from its conception through to its demise in 2006, has found that, while government rhetoric behind the GKP initiative was outwardly, centred on a 'Mode 2' ideology, the institutionalised practices of policy makers and government departments involved in managing it were, underpinned by a 'Mode 1' approach. This we will argue has had unintended consequences for processes of knowledge production not only restricting opportunities for translation, but also actively disrupting collaborative working amongst scientists and other practitioner groups.

*Author(s)* A Metcalfe, J Werrett & L Burgess
*Institution(s)* School of Health Sciences, University of Birmingham, UK
*Title* Using personalised genetic risk information more effectively: Implications for policy and practice

Little is known about where people get genetic risk information from or how they use that information to assess their own personal risk and respond to it. Increased insight into patient/clients' needs could lead to more tailored information and genetic risk counselling to improve decision-making for those at high risk, whilst reducing anxiety for those at lower risk. This study aimed to identify the information needs of patients referred because of their concerns about a genetic predisposition to cancer, and explore how information needs and other relevant variables affected risk perception and cancer worry.
N=1114 patients referred for genetic counselling because of concerns about an inherited predisposition to cancer were surveyed 2-4 weeks prior to them receiving their personalised genetic risk assessment. The structured questionnaire survey explored participants information needs, level of perceived risk, cancer worry and a range of demographic and psychosocial factors which were likely to affect these components; stratified by their assessed risk level and cancer type.
518 participants (47%) responded. Irrespective of a person's actual or perceived risk level, or other demographic variables, priorities in the type of information required were similar. Greatest emphasis focused on information provision about how risk was assessed; least important was acquiring an understanding about inheritance patterns. The results provide clear indications that general practitioners are probably the most relevant people to raise concerns about genetic cancer risk rather than hospital consultants or other family members.
This study provides detailed insight into how cancer genetic risk information may be more effectively communicated to patients/clients tailored to their personal level of risk, and provide evidence of the important role of GPs in genetic risk communication with implications for future healthcare practice and policy.

Author(s) E van Rijswoud[1], D Stemerding[2] & T Swierstra[3]
Institution(s) 1 Department of Philosophy and Science Studies, Faculty of Science, Radboud University Nijmegen, NL
2 Department of Science, Technology, Health and Policy Studies, University of Twente, Enschede, NL
3Department of Philosophy, University of Twente, Enschede, NL
Title Shaping the agenda in the field of genetics and public health: an interactive scenario study

As part of the first five-year research programme of the Centre for Society and Genomics, an interactive scenario project has been carried out, exploring the future prospects of genetics in public health. In the Netherlands and internationally, we see attempts to move from established practices of clinical genetics to more wide-ranging practices of community genetics, with the aim to create ways in which genetics and genomics may be used on a broad front for new prevention oriented forms of public health. In our project we have studied the agenda of community genetics and translated this agenda in future scenarios. These have been discussed with various actors who are, or might become involved in the realization of this agenda in future practices of genetic and genomic medicine. In these scenario's we focused on a number of salient tensions and dilemma's, which we expected to become particularly relevant with regard to the future agenda of community genetics. We showed how these tensions and dilemmas might materialize in a series of events unfolding in three different spheres of the future Dutch health care landscape: public health care, commercial care, and primary care. We subsequently used the scenarios as a basis for discussion and reflection in workshops with different stakeholders.

The workshop discussions clearly showed that we should distinguish genetics and genomics as two fields which, in thinking about the future, raise different kind of questions. In the context of Dutch public health policies, genetics raises questions relating to the implementation of available options for population screening, whereby the decision-making responsi-

bility of the government is taken for granted. In this context, public health priorities and financial constraints are seen as the major uncertainties. Genomics, on the other hand, is a major priority in the research policy of the Dutch government, but the relevance and impact of genomics for health care are generally considered as highly uncertain and controversial. In this context, commercial and consumer interests may become much more decisive in embedding genomics in the health care landscape than governmental policy. In this panel session we would like to present and discuss the project's findings and its implications for the short and long term challenges in governing genetic and genomic medicine in society.





*Author(s)* E Aarden
*Institution(s)* University of Maastricht, NL
*Title* **Broadening the agenda for genomics and society; practices of provision in health care genetics**

Recent developments in human genetics research have clearly contributed to a better understanding of the role of genes in certain diseases. For some commentators this has been reason to start speculating about an upcoming genetic revolution in health care.
Following such claims, much ELSA work on genetics and health has criticized such comments by looking at health care genetics in practice. This kind of studies has often focused on the micro scale of clinical interaction between medical professionals and patients and the practice of medical genetics. In brief, the main argument brought forward in studies of this kind is that genetic medicine consists of a complex of techniques, actions and interpretations on the side of professionals as well as patients to construct genetic diagnosis for a variety of diseases.

Yet in arguing – correctly – that genetic medicine is constructed in practice and not determined by the development of new technologies in the lab, much social science works on genetics pushes the question of broader implications of genetics off the agenda. One area where such implications occur is the availability of health services in social health care structures in Western Europe. These structures are under pressure to reform, but at the same time need to accommodate developments in medicine, such as those in genetic diagnosis. By drawing on examples from my research I will argue that new medical technologies and the structure of health care delivery are co-produced in the practice of negotiating, setting and applying standards and criteria for provision of genetic services, redefining the moral objectives of social health care along the way.

*Author(s)* B Wieser, D Freitag, S Karner & W Berger
*Institution(s)* IFZ: Inter-University Research Centre for Technology, Work and Culture, Graz, Austria
*Title* **The contextualisation of genetic testing in reproductive care**

Prenatal testing has become a routine practice of antenatal care. According to international standards informed consent is a requirement prior to testing. However, due to the introduction of nuchal translucency measurement and the combined maternal blood test, this arrangement is undermined in some important ways. There is a tendency that counselling starts not before the first screening, but only if the results are conspicuous.
Austria is a special case in this respect. Antenatal care is organised in a comprehensive programme that is mandatory for all pregnant women. The aim of this programme is to secure the wellbeing of both the mother and her child. We argue that because of the contextualisation of nuchal translucency measurement into the routine antenatal care it is difficult for pregnant women to distinguish between mandatory and elective examinations of antenatal care. This is especially relevant for the quality of informed consent that can be achieved in prenatal screening and subsequent diagnostic testing of the foetus.

The presented case addresses core issues of the conference theme. The Austrian health care policy can be regarded to be rather paternalistic. This is especially true for the mentioned antenatal care programme which was designed and implemented in the 1970s. Considering that the informed patient has now become a guiding vision of health care also antenatal care faces a demand for change of professional practices. This, however, requires a change of policy practices as well as a wider public debate on health care issues.


*Author(s)* M Sleeboom-Faulkner
*Institution(s)* University of Sussex, UK

*Title* Tacit Collaboration in Bioethics: Human embryonic stem cell research and new biocultures in Mainland China

In second millennium Asia, various countries became known for the advantage they would have in developing the life sciences: the so-called bioethical vacuum. This paper explores the process in which Mainland China's life sciences' reputation evolved from an 'bioethical vacuum' into the bio-culture of Chinese ethics.

The paper, based on four months of fieldwork and forty interviews with scientists held in 2007, explores how bioethical regulation came about by placing the personal experiences of stem cell scientists at home and oversees in a historical and institutional context. It discusses the historical background of the life-science in Mainland China and the 'ethics' that plagued its development. It discusses the development of bioethical regulation of stem cell research by referring to the development of official regulation and discussions in medical textbooks for students. And, finally, it explores the interpretation of bioethical regulation by referring to the personal views of scientists in various stem cell research fields, institutional circumstances, and aspects of their overseas experiences.

On the basis of these data, I discuss how, even in a situation of independent research practice, bioethical guidelines are formed while keeping in mind the collaboration with imaginary or potential collaborators. Here various factors play a role, among which the promises of discovery and the possible investments by pharmaceutical companies, potential collaboration with foreign researchers and the aim of publishing in internationally peer-reviewed journals.



# SESSION IV-D
# THE ROLE OF TRUST IN THE PUBLIC ACCEPTANCE OF GENOMICS

*Session organisers* C Critchley, E Hardie & R Pin

Trust has been found to be a key factor in the process of public perception and acceptance of genomics applications. In this session we explore several studies in which trust was assessed in relation to various emerging technologies: stem cell research, therapeutic cloning, genetic profiling for health promotion purposes and personalized nutrition based on one's gene-structure. We will discuss the role of trust and explore the differences and similarities between the different applications. Implications of trust and public reactions for the development of these technologies will be discussed.


*Author(s)* C Critchley
*Institution(s)* Faculty of Life & Social Science, Swinburne University of Technology, Australia

*Title* Commercializing controversial research: What are the consequences for public trust?

Much has been written about the effects of commercialization on the integrity of scientific research. Yet little is known regarding the impact on public opinion and trust. This research investigates change in public attitudes and trust across private and public contexts using the examples of human embryonic stem cell research (Hescr), therapeutic cloning and the ownership of genetic information. The results from five national Australian telephone surveys (n = 1013; n = 1013; n = 1000; n = 1000; n = 1208) consistently suggest that respondents were significantly less comfortable with private companies conducting research and owning genetic material than public universities. Multilevel and structural equation modelling revealed that trust in scientists, the organization, and the funding source were found to significantly account for the decrease in comfort. University scientists were trusted more than private scientists because they were perceived to be motivated more by benevolence, and more likely to produce benefits that will be accessible to the public. Overall the findings imply that support for controversial research is reliant on perceptions of who is conducting the work and why. The results also suggest that Australia's relatively high level of support for stem cell research is partly due to a belief that it is funded and controlled by public interests. The potential effects of eroding this belief on public trust and attitudes will be discussed.


*Author(s)* E Hardie & C Critchley
*Institution(s)* Faculty of Life & Social Science, Swinburne University of Technology, Australia

*Title* Community responses to a hypothetical scenario involving genetic profiling for health promotion purposes: trust and other reasons for behavioural intentions.

Trust in medical experts is likely to influence public acceptance of new genetic technologies. To test this proposition we conducted a national telephone survey of 800 Australian

adults. Vignette methodology was used to assess community responses to a hypothetical doctor. After describing the expertise of "Dr Benson" in the use of genetic profiling for health promotion and disease prevention, respondents were asked how much they would trust the doctor, how likely they would be to have their genes profiled by this doctor, and the reasons behind this intention. Quantitative and qualitative analyses were used to provide a profile of those who were most or least likely to seek genetic testing to promote health and prolong life.


*Author(s)* R Pin[1], C Critchley[2] & E Hardie[2]
*Institution(s)* 1 Behavioural Sciences, University of Twente, Enschede, NL
2 Faculty of Life & Social Science, Swinburne University of Technology, Australia


*Title* **The role of trust in public perception of personalized nutrition: A comparison of Australia and The Netherlands**

If genomics technology is able to predict diseases and prescribe preventive diets based on a person's genes, it is important to understand the public's intention to adopt such personalised diets. Based on the existing literature, several cognitive-affective factors which might influence this process have been identified. The aim of the present study is to bring together in one model the intention to adopt personalized nutrition and the cognitive-affective determinants of trust, cost/benefit ratio, perceived consequences, perceived value of science and affective evaluation. We conducted survey research among representative samples in The Netherlands (n = 2109) and Australia (n = 1000) to explore cross-cultural differences and test the fit of the model for both populations using structural equation modelling.



# SESSION IV-E
# GENOMICS EDUCATION THROUGH IMAGINATION

*Session organiser* N Wieringa


*Author(s)* N Wieringa1, H van der Windt[1], T Maples[2], M Verkerk[3], L Dijkhuizen[4], R Vonk[5], J Swart[1]
*Institution(s)* 1 Science & Society Group, University of Groningen, Haren, NL
2 Pandemonia Science Theatre, Amsterdam, NL
3 Medical Ethics Department, University Medical Center Groningen, NL
4 Microbial Physiology Research Group, University of Groningen, NL
5 Lab of Nutrition and Metabolism, University Medical Center Groningen, NL


*Title* **Qualitative analysis of a science theatre play about nutrigenomics, food technology and lifestyles**

Science theatre has been introduced as a novel form of science communication. In collaboration with Pandemonia we developed a science theatre play in order to evaluate its merits as an interactive way of conducting science communication targeting a specific group. Science theatre links education and entertainment, and provides an arena for interaction and debate aiming to stimulate reflection on social and scientific developments. This theatre play is about food and personal dietary habits in the context of societal and scientific issues such as obesity, nutrigenomics, personalized diets and functional foods. After the play two statements are debated with the audience. 15.000 pupils of 4th and 5th grade pre-university and senior general secondary education at 70 schools in the Netherlands attended the performance.
We conducted a qualitative evaluation study of the theatre play and the debate. The developers of the intervention were asked to reflect on the intended goals and background of this form of science communication. Furthermore, we interviewed pupils in focus groups on positive and negative aspects of the play and the debate, and issues they had reflected on. Lastly, semi-structured interviews were held with 11 persons representing various fields of expertise, including science communication, ethics, psychology, and related biomedical sciences. Interviewees were asked about the possibilities and limitations of the intervention.
The results of the study will be discussed, thereby distinguishing between generic and specific aspects of science theatre. We think that the results of this study will provide insight in science theatre as a tool in agenda setting and implementation of science communication.


*Author(s)* F Ticehurst1, L Osborn2, B Williams3, P Gibbins4 & J Davies4
*Institution(s)* 1 Wales Gene Park, Cardiff University, UK
2 Freelance Writer, Cardiff, UK
3 Genetic Interest Group, London, UK
4 Gwent Theatre Company, Abergavenny, UK


*Title* **Boy Genius: Exploring Genetics through Interactive Theatre for Young People**

The Wales Gene Park recently collaborated with the Genetic Interest Group and Gwent Theatre to develop and produce an interactive theatre workshop exploring contemporary

developments in human genetics for young people from schools and colleges across Wales. The collaboration combined expertise in the science and the social and ethical aspects of genetics, science communication and in developing drama techniques for education. The main aim of the project was to use an innovative and creative approach to engage young people and encourage understanding and appreciation of different aspects of a complex area of biomedical science and the associated social and ethical issues. The project was funded by a Wellcome Trust Public Engagement Society Award.

Working with a writer, the project team developed an innovative and challenging drama centred on a young man's experience of mental illness. The performance explored questions and issues related to genetics and mental health including those surrounding family relationships, expectations of 'normality' and social responsibility. The young people's participation was task driven and structured to facilitate an intellectually and emotionally stimulating learning experience, requiring them to take an investigatory and mediatory role in the drama. Additional educational resources for use in school extended the learning experience beyond the activity itself.

This interactive presentation will demonstrate aspects of the methodology used within the project and considers how these sought to activate the imaginations of the participants in their understanding of the story, the underlying concepts and the issues it raised.

*Author(s)* F Meulenberg[1], I de Beaufort[1], MC Knippels[2], S Severiens[2]
*Institution(s)* 1 Department of Medical Ethics and Philosophy of Medicine, Erasmus University Medical Center, Rotterdam, NL
2 Rotterdam Institute for Social Policy research, Erasmus University, Rotterdam, NL

*Title* **Education through fiction. The effects of images, icons and ideas on moral reasoning about genomics**

This study examined the outcomes of a newly designed science module (a series of four lessons) on moral reasoning in the context of genomics in upper secondary education. The aim of the educational unit was to foster sixteen-year-old students' opinion forming skills in the context of genomics and to test the effect of fiction on their opinion forming skills. The basic hypothesis is that fiction stimulates students to develop their opinion in socioscientific issues. A quasi-experimental design was used with treatment groups ('fiction' and 'science'), control groups and pre- and post-test to test this hypothesis.
266 secondary school students answered a questionnaire to test their opinion forming skill and up-to-date knowledge of genomics. Results showed that the science module had a significant effect on students' opinion forming skills (defined as a combination of number and type of arguments, use of knowledge to construct their opinion and incorporation of alternative perspectives in the fiction group. The module did not affect opinion forming skills in the science group nor the control group.
It may be concluded that the use of fiction materials to introduce a socioscientific issue in the classroom stimulates students to develop their opinion forming skills.

As a result our research will describe the necessary conditions for education in genomics to be effective, using fiction (i.e. novels and movies). The findings of the study, including the advices for the public debate will be presented and discussed.

# SESSION IV-F

# GENOMICS KNOWLEDGE AND THE SELF

*Author(s)* M Silvestric & R Kollek
*Institution(s)* FSP BIOGUM / FG Medizin, University of Hamburg, Germany
*Title* Breast cancer as boundary object – Impacts of genetic research on clinical practice

Breast cancer as a concept and material object frames the discourse and the daily routines in gynaecological oncology as well as in corresponding oncological molecular-biological research. In doing so, breast cancer acts as a boundary object existing in both social worlds and shaping the conceptual boundaries of the fields of work. Existing in both worlds, the boundary object enables communication across disciplines and the translation of knowledge towards other research communities or towards the concept and classification of breast cancer itself from every participating side.

The focus of this paper lies on how new analytic and diagnostic methods affect the conceptualization of breast cancer and clinical practice. Stressing the impact of microarray-studies, the paper analyses the growing importance of genetics on the characterization and classification of malignancies. Emphasis is put on the translational process between the worlds of molecular biology and clinical practice and how this translation influences the conceptualisation of the boundary object itself. The main aim of this paper is to provide insight into this interference which is cooperating and competing at the same time; it will also describe the interactions of different social and scientific worlds with a common boundary object and its modification. It is hypothesized that such processes are a common phenomenon in current interdisciplinary research and that their study will have interesting implications for future research agendas.

*Author(s)* F Tomasini
*Institution(s)* CESAGen, Lancaster University, UK
*Title* Trustworthiness, personalised nutrition and nutrigenomics

The concept, trustworthiness, is explored as a capacity of human agents to reliably tell the truth about a state of affairs to others and/or to resist self-deception about what that state of affairs actually corresponds to. The trustworthiness of a source of promotion, advertising and or labelling is brought into question when it no longer adheres directly to truth telling or the competence to recognise what is true and what is highly contentious or ambivalent. This has two direct policy implications in the promotion, advertisement and labelling of functional foods that offer a personalised nutrition benefit through nutrigenomics. The first policy implication for trustworthiness is the deliberate and conscious effort to be truthful and not to deceive others. Trustworthiness as the capacity for truth telling can be defended from a Kantian perspective. That is, any conscious deception, for whatever reason, is simply not rational if the agent is to remain a trustworthy source of information as to actual health benefits of functional foods that make any claim to a personalised nutrition. The second policy implication for trustworthiness is the self-reflexive ability not to deceive oneself. That is, as well as being purposively deceptive, the promotion advertising and labelling of personalised nutritional products are often ambivalent, in which the agent promoting the product deceives themselves in order to deceive others (their customers) more successfully. Self deception as 'bad faith' from a Sartrean perpective, undermines any competence to make any nutritional claims at all.



*Author(s)* J Vailly
*Institution(s)* Institut de Recherche Interdisciplinaire sur les enjeux Sociaux (IRIS), CNRS-Inserm-EHESS-Université Paris 13, France
*Title* Expanding abnormality: neonatal screening, prenatal diagnosis and cystic fibrosis in France

In a previous study, I showed that neonatal screening for cystic fibrosis in France was to a large degree a political technique of government (Foucault) based on a biomedical technique, i.e., a medical collective was enjoined to follow protocols and patient families were led to bring their children to specialized centers. My survey was followed up by a study of the regime of practices involved in the screening. It is based on observation of meetings between paediatricians and geneticists implicated in the screening programme, and a seven-month study in a tertiary care centre for cystic fibrosis. On the one hand, it highlights the technical limitations of screening, which have the effect of expanding biological abnormality in the case of newborns. On the other, it deals with the rationales and associated practices used by health care professionals for paediatric monitoring; it is in these rationales and practices that the expansion of clinical abnormality originates. Lastly, it analyses the consequences of those practices at the interface between neonatal screening and prenatal diagnosis, showing how the biomedical norm, with respect to foetuses, is altered. A discussion on this development will be suggested.

# SESSION V-A
# PUBLIC & PROFESSIONAL CONCERNS

*Author(s)* R Verhoeff & AJ Waarlo
*Institution(s)* Freudenthal Institute for Science and Mathematics Education, Utrecht University, NL
*Title* **Finding common ground for public dialogue on cancer genomics**

Genomics innovations have increasing impact on individuals and society. In cancer genomics new innovations related to prevention, diagnosis and treatment of the disease will change daily routines in academic research, medical practice (diagnostic lab, doctor-patient communication), and everyday life. To further public dialogue on cancer genomics, members of these different communities of practice should be enabled to learn from each other. Yet, although communities overlap and interact, mutual communication and sharing of knowledge may be problematic due to differences in value systems and knowledge modes, i.e. academic, professional and experiential. Recently, we conducted a case study on a public event on cancer genomics and found that achieving a dialogue in practice is not self-evident and needs commitment at the institutional as well as the interpersonal level. This paper describes the follow-up of this case study and takes up the challenge to find the common ground for communication between different communities of practice. Our main research question is: How do relevant communities of practice view one's own and each others role in public dialogue and how can these views be translated to find common ground for communication. In this paper we provide a start in articulating the conceptual and normative elements of this common ground based on interviews with representatives from different communities of practice, i.e. cancer genomics researchers, doctors and patients. This provides indications for empowering scientists and medical professionals to reflect on the social and ethical dimensions of their work.

*Author(s)* A Dubois
*Institution(s)* Faculty of Pharmacy, University of Montreal, Quebec, Canada
*Title* **How to lead the implementation of pharmacogenetics (PGx) in the agenda setting?**

The application of PGx in medical practice is delayed by some barriers: the lack of strong regulation for home-brew tests, the lack of evidence for the evaluation of clinical utility and the cost-benefits needed for resources allocation decision and elaboration of practice guidelines. How will these barriers affect the local translation of PGx in difficult context practice? A qualitative study was designed to evaluate the impact of these issues in Quebec (Canada). Quebec has considerable advantages to be a leader in genomic research: support of public and private investors, outstanding researchers and cutting edge infrastructures. Though, Quebec has no regulation and initiatives to translate the generated innovations in its limited resources public health system. First, an analysis of the Canadian and Quebec literature related to Pharmacogenetics (1990 to 2006) was performed. Second, twenty multidisciplinary experts currently involved in the implementation of pharmacogenetic and genomic approaches in Quebec medical practices were interviewed. For all discourses, three principal concepts were drawn: 1)The positioning and social representations of pharmacogenetic; 2)The advantages, risk and challenges related to this application; 3)The existing barriers, as well as the most popular concepts with regards to the integration of pharmacogenetics in the Canadian practice. Results show a deficient organizational context due to unbalance investment in research and health system and a lack of health policy. Furthermore, pharmacogenetics utilization is limited, fragmented and not standardized. Initiatives are needed at an International, National and Provincial level to give professionals the tools to deliver quality services equitably.

*Author(s)* K Getliffe
*Institution(s)* Egenis, University of Exeter, UK
*Title* **What Role Does Public Concern Play in Setting the Agenda in the Regulation of Genomics?**

Agenda setting and the political attention cycle in the regulation of genomics will be discussed principally with reference to the interaction of three agents: the technoscience per se, the regulators and the public. Thus the extent to which technological developments in genomics emerge and set the political agenda will be discussed with reference to the funding behind the research and the commercial applicability of products. Secondly, the ways that public attitudes are included and excluded from policy making and regulatory output are analysed. The role that regulators and independent regulatory agencies (IRA) play in shaping the regulation is drawn out with reference to two case studies: GM foods and prenatal testing, including pre-implantation genetic diagnosis (PGD). Empirical findings derived from analysis of the British Social Attitude Survey (BSA) and Eurobarometer survey data are referred to in conjunction with longitudinal regulatory mapping which contextualises the weighting given to public concern by regulators.
I will tease out the relationship between the public and the regulators in the second stage with reference to the thermostatic model of policy-making (Soroka and Wlezien 2005). The thermostatic model asserts that when the public acts responsively to policy, there is an incentive for policy makers to produce policy which is responsive to the public's wishes. As such a thermostatic relationship develops where the public's 'temperature' is gauged at regular intervals in terms of whether there is a desire for greater or reduced policy intervention. The relationship between the IRAs and the weighting given to public concern will be framed according to the theory of punctuated equilibrium (Jones & Baumgartner 2005, Timmermans & Scholten 2006).

# SESSION V-B
# AUTONOMY & PRIVACY

*Author(s)* E Vermeulen
*Institution(s)* The Netherlands Cancer Institute, Antoni van Leeuwenhoekziekenhuis (NKI/AvL), Amsterdam, NL
*Title* **Autonomy reconsidered: An 'opt out procedure' according to patients' wishes**

Tissues excised for medical treatment and diagnosis can, in the Netherlands, based on the law on patients rights (WGBO 1995) and the code of conduct of the Dutch Federation of Biomedical Scientific Societies (FMWV) 'Proper secondary use of human tissue' (2001), be used in scientific research unless the patient 'opts out', i.e., actively declares that remaining tissue may not be used in research. Hospitals inform patients about tissue and research and the right to 'opt out' of research in patient information sheets; patients are not actively asked for consent.
There is – international – debate whether such an 'opt out' regime is appropriate and according to patients' wishes. The current Dutch government wants to promote both patient autonomy and access to remaining tissue for researchers by means of a new bill.
In explorative research funded by the Cancer Genomics Centre we found that Dutch patients prefer an amended 'opt out procedure'. The paper will summarize the research findings of three different research projects and propose a procedure for informing patients and facilitating patient autonomy by combining 'opt out' with a consent regime that provides control over future tissue research.
The procedure patients preferred can be characterized by verbal information to the patient about tissue storage and the option to opt out. Patients do worry about specific uses of tissue, especially in 'commercial research' and therefore they prefer to also have the option to have access to (written) information about research with remaining tissue. With the amended opt out procedure the patient can determine what is worth knowing and which decisions are important enough to be contemplated. The procedure secures that all patients are informed on a level that suites their needs will therefore facilitate trust in research.

*Author(s)* A Krajewska
*Institution(s)* ESRC Centre for Genomics in Society (Egenis), University of Exeter, UK
*Title* **Genetic anti-discrimination law – need for reconceptualisation?**

Policy makers often see discrimination on the grounds of genetic characteristics as the biggest threat to human dignity and autonomy arising as a consequence of the use of genetic information. To date many attempts have been made at the International, European and national level to prevent the so cold geneticism – a term created to describe the vision of a new form of social stratification based on genetic features.

The UNESCO Declarations on Human Genome and Human Rights and Human Genetic Data (2003) adopted the most straightforward approach explicitly forbidding the use of genetic data for discriminatory purposes. The Charter of Fundamental Rights of the EU (2000) extended the scope of the non-discrimination principle by adding "genetic features" to the list provided in art. 21 which sets out grounds on which discrimination is forbidden under EC law. Similar provisions tend to appear in a number of draft national legislation concerning genetic testing and biobanks. Until now none of these legal instruments has become legally binding. Yet, as a result of the EU summit in Lisbon in December 2007 the EU Charter is expected to gain legal force together with the Lisbon Treaty in 2009. Along this line in September 2007 the British Human Genetic Commission agreed to support measures to outlaw unfair discrimination based on genetic differences by proposing amendments to the Equality Act. This approach requires careful reconsideration.

Although genetic testing and the subsequent use of genetic information/data pose serious threat to the exercise of equality principle and human rights, I argue that the provisions banning genetic discrimination in the form stipulated in the International documents are not operational. The main argument against this approach is strictly related to the criticism of genetic exceptionalism, which indicates the practical impossibility of distinguishing between genetic and other health data, stemming from the complex interdependence of genetic and environmental factors. A broad interpretation of the ban would allow the subsumption of features which are determined by an unknown mix of genetic and environmental factors under the term "genetic". On the other hand, limiting the scope of anti-discrimination principle to the genotypic ("hidden") data allows discrimination on the ground of phenotypic data or family history, leading to even more discriminatory effects.

Therefore, since the aim of the genetic anti-discrimination law is to prevent discrimination on the grounds of predictive information about our future health, what should be considered is a complex context-based regulatory framework encompassing all highly predictive data about future and still not visible characteristics (Huntington disease as well as HIV), regardless of whether they are of a genetic or non-genetic origin.

*Author(s)* J Wright
*Institution(s)* Sheffield University, UK
*Title* **Privileged Project - Key Findings on Public Attitudes Towards Privacy in Genetic Research**

PRIVILEGED (www.privilegedproject.eu) is a three-year EC-funded project looking to determine the ethical and legal interests in privacy and data protection for research involving the use of genetic databases and biobanks. This paper will present the results from stage one of the project which aimed to explore what people think their privacy interests are in relation to the use of genetic data in such research.

Partners in the PRIVILEGED project from 26 European countries plus Israel, Japan and Taiwan, have been asked to complete questionnaires analysing public attitudes in this area within their own country. These responses will be analysed and compared before the first project workshop in January 2008, which will discuss the preliminary results.

Stage one of PRIVILEGED also aims to: analyse the foundations of any elucidated privacy interests within the countries; consider group privacy interests; consider whether any indicators underlie similar privacy interests across countries; compare the views from a regional

perspective; discuss the legal situation in each country; consider whether privacy interests may be changing over time; and ask whether we are moving toward, or away from, a common set of privacy values in the context of genetic data research in European culture and society?

This paper will present the key findings from stage one of the PRIVILEGED project after they have been revisited and re-assessed as a result of the Workshop.



# SESSION V-C
# GENOMICS AND IDENTITY

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2 CESAGen, Lancaster University, UK
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4 Department of Primary Health Care and General Practice, Imperial College London, UK
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## *Title* Reviving 'Racial Medicine' ? The use of race/ethnicity in genetics and biomedical research, and the implications for science and healthcare.

Science has a long, and many would argue tarnished, history of trying to use the concept of race/ethnicity in research. In the post-genomic era of biomedical science, some scientists are consigning race/ethnicity to the scrapheap, while others are apparently reviving it to enable the development of more 'targeted' diagnostics, therapeutics and health services. To explore this apparent contradiction, the Wellcome Trust funded a three-year interdisciplinary research project to address two questions. First, how is race/ethnicity used in genetics and biomedical research? Second, what are the likely implications of this usage for science and health care? During the research we interviewed a purposively selected sample of UK scientists, civil servants and health services researchers, and undertook the analysis of a range of documentary sources. In this session we present some of the key findings from the project. These will include: the practice of adopting of socio-political classification systems (e.g. census categories) into biomedical science research; and, a conflict facing researchers between the imperatives of 'social inclusivity' and 'analytical acuity', which can lead to racial/ethnic minority groups being excluded in research design or in data analysis. The interactive agendas format provides an opportunity to discuss these findings (and their implications) with a panel of policy-makers, professionals and genomic researchers.

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2 Foundation for Tracing Hereditary Hypercholesterolemia (StOEH), Amsterdam, NL
3 Psychology & Genetics Research Group, King's College, London, UK

## *Title* Health threat representations and preventive behaviour in people diagnosed with Familial Hypercholesterolemia by DNAtesting

**Background**

Familial Hypercholesterolemia (FH) is a genetic disorder characterised by a family history of cardiovascular disease (CVD) and premature symptoms of CVD. The aim of the present study is to describe health threat representations and preventive behaviour of people diagnosed with FH by DNA-testing and to identify factors that are associated with preventive behaviour using Leventhal's Common Sense Model as a framework.

**Methods**
Health threat representations (including perceptions of CVD-risk) and preventive behaviour of 81 FH screened positives were assessed by self-administered questionnaires.

**Results**
Participants perceived genetic factors as a more likely cause of CVD than unhealthy diet and lack of physical activity and considered medication as a means to reduce CVD-risk as more effective than a healthy diet and sufficient physical activity. A majority perceived their risk as similar or lower to others their age. Verbal perception of risk was positively correlated with the number of affected relatives, having high cholesterol and considering CVD as a permanent condition. Of all hypercholesterolemics, 90% reported using cholesterol-lowering drugs and only 11.1% of participants indicated that they were smokers. However, only 50% reported following the recommendations concerning diet and physical activity. Multiple regression analysis showed that the number of affected family members and perceived efficacy of a healthy diet and sufficient physical activity explained 26% of the variance in diet and physical activity behaviour.

**Conclusion**
In their communication with screened positives, it may be advisable for health professionals to explain that although medication can be effective in lowering cholesterol levels, it will not reduce CVD risk to normal levels and therefore appropriate lifestyle adjustments will still be necessary.


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4 EMGO Institute, VU University Medical Center, Amsterdam, NL;
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*Title* **An offer of combined ancestrybased preconceptional carrier couple screening for cystic fibrosis and hemoglobinopathies: response in a multiethnic population**


Purpose: To study the response to an offer of combined preconceptional ancestry-based carrier couple screening for cystic fibrosis (CF) and hemoglobinopathies (HbPs), in a multiethnic population in the absence of a preconceptional health care setting.
Methods: 9453 people (20-35 years), including 50-60% non-Western immigrants, were invited to visit their general practitioner (GP) within one month with their partner for the screening test(s). They received the invitation from their GP (n=4720) or the Municipal Health Service (MHS) (n=4733). Invitees with a partner and planning a pregnancy were the target population. Eligibility for CF and/or HbPs carrier screening was determined with a validated ancestry-based decisional instrument. Data were gathered by questionnaires.
Results: One third of the invitees belonged to the target population. A total of 1365 invitees responded. 166 (34%) of the 490 invitees who belonged to the target population intended to participate in the test(s), but 87 actually did. Compared to all invitees, less participants had been invited by the MHS (29%)($p<.001$), were non-Western immigrants (31%) and had a lower level of education (10%). 3% of the target population participated in CF and/or HbPs carrier screening. "I'm too busy" (21%) was an important reason for non-participation. The majority (73%) favoured offering these test(s) routinely to all couples planning a pregnancy.
Conclusion: The gap between intention to participate and actual participation in the test(s), as well as the lower uptake among non-Western immigrants, lower educated individuals and MHS-invited people, lead to challenges for the implementation of preconceptional ancestry-based CF and/or HbPs carrier couple screening.

# SESSION V-D
# NEW PERSPECTIVES ON MORAL EDUCATION IN GENOMICS

*Session organiser* AJ Waarlo

*Author(s)* J Lewis
*Institution(s)* Centre for Studies in Science and Mathematics Education, University of Leeds, UK
*Title* Classroom discussion of socioscientific issues. The role of genomics knowledge

This contribution considers the relationship between science knowledge and the ability to engage in reasoned discussion of the social consequences of science. Through a study of over 200 school students aged 14-16 we show that the ability to engage in reasoned discussion of applications of gene technology is strongly influenced by the ability to recognize key issues, and that ability to recognize key issues requires some understanding of the relevant science. It is also influenced by the specificity of the context under discussion and personal experience. The requisite scientific knowledge base is relatively modest and can be effectively taught through brief teaching interventions that are well designed and contextualized. The implications for classroom practice are considered.

*Author(s)* P van der Zande & AJ Waarlo
*Institution(s)* IVLOS, Institute for Teacher Training, Educational Development and Academic Skills, Utrecht University, NL
*Title* Dealing with controversial genomics issues in the classroom. Mapping teachers' expertise and students' informal reasoning

Although sound conceptual knowledge improves argumentation skills, this knowledge doesn't always change our decision. Indications are growing that we make our moral decisions based on intuition. We use our arguments only to defend our position after it is taken intuitively. Our usual rational approach of moral education could be rendered out of date by these new insights. Which pedagogical approach will help us to incorporate intuition into moral education and how can science teachers master that approach? This is the main research question of the project which aims at understanding and improving the development of teacher's expertise entailed in dealing with controversial issues on genomics.
The project started with outlining current moral education in biology classes by reviewing science education literature and interviewing good practice teachers to elicit their practice expertise. In addition, students have been confronted with issues on prenatal diagnosis and genetic testing to probe their reasoning pattern before being taught about genomics.
This presentation will report the research findings of the first part of this project and implications for educational practice will be discussed.



*Author(s)* DJ Boerwinkel & AJ Waarlo
*Institution(s)* Freudenthal Institute for Science and Mathematics Education, Utrecht University, NL
*Title* New strategies for moral education in genomics

Many learning and teaching strategies in moral education are based on argumentation models for reasoning. However, new psychological insights into the process of decision-making indicate that decisions are often made intuitively, and that arguments are used afterwards to justify and communicate an already taken decision. This does not mean that decisions are not influenced by arguments, but suggests that a large part of the process of weighing pros and cons is hidden from introspection.
This should have implications for learning and teaching strategies in moral education.
Using argumentation models in moral education to help students to communicate and justify their opinions, might not directly influence their opinion forming. Alternative pedagogical approaches in which emotions and images are addressed could be more effective. Among these are fiction and gaming. Some examples of these will be discussed in the context of opinion forming about cancer genomics.

# SESSION V-E

# SHARING EXPERTISE: ELSA GENOMICS FROM RESEARCH TO BOARDROOM?

*Session organisers* E van Rijswoud, H Zwart & H te Molder

As the theme to the conference indicates, ELSA genomics research is maturing and becoming ever more relevant for policy and professional practices. In some instances, social scientists, lawyers or philosophers interact in their research directly with those who have the potential to shape societal, political, professional and academic agendas for genomics. In others cases research that thus far remained at a certain distance from political and professional practices has the potential to improve these practices. In all, it is clear that ESLA genomics researchers individually and collectively have risen to being valuable experts, whose expertise is indispensable in setting the agendas.

However, the combination of different sorts of expertise in the public sphere – one of the preconditions for ELSA research to be effective - is still a delicate matter. A robust collaborative interaction between science and society not only requires a better understanding of the publics, but also more insight into the actual and desired role of experts. Practice and research show that there is more to expertise than 'speaking truth to power'. In this session, we focus on the role of scientific experts. How do experts conceptualise their task as part of, and in relation to society? How is their specialist knowledge to be integrated with other relevant perspectives and considerations? Recently, Collins and Evans (2002) have proposed a normative turn in science and technology studies (STS), with a specific focus on the role of experts and expertise. Their categorization of different sorts of expertise has given rise to a vivid and profound discussion about what expertise comprises and how it can be recognized. At the same time, their call for disentangling political rights in technical decision-making from entitlements to expertise has also evoked strong criticism.

These ideas are valuable to the ELSA researchers, but they cannot be 'applied' instantaneously. In this session we will invite key 'experts on expertise' from STS and communication studies to discuss how ELSA genomics researchers can share their expertise in a constructive manner. Robert Evans will present the typology for expertise which he, together with his colleague Harry Collins, has developed over the years. In this typology, interactional expertise is a key phrase: it refers to the ability of an expert "to master the language in a specialist domain in the absence of practical competence" (Collins and Evans, 2007).

This ability is highly relevant for ELSA genomics researchers; although many have mastered the intricacies of genomics technology, those coming from social science will lack practical skills. But beyond mastering the language of genomics, the challenge now is to master a different language: that of boardrooms and parliament. What can we learn from Collins' and Evans' work in sharing our expertise in the practical contexts of decision making? And what do we actually expect from genomics researchers with regard to their expertise?
This will not be a crash course in how to be an expert, but a session that aims to stimulate our reflection: how can we, as ELSA genomics researchers, use our expertise in setting the agendas? First, Evans will present his typology and some key points on the use for ELSA genomics. Then the other speakers will reply to Evans: what are its uses from ELSA genomics researchers, what its problems? Are there actual examples of best practices?

| | |
|---|---|
| *Speaker(s)* | R Evans |
| *Institution(s)* | Cardiff University (UK) |
| *Title* | Rethinking Expertise: What's in it for ELSA genomics researchers? |
| *Speaker* | A Irwin |
| *Institution(s)* | Copenhagen Business School, Denmark |
| *Title* | Response to Robert Evans |
| *Speaker* | PB Joly |
| *Institution(s)* | Science & Gouvernance', Institute National de la Recherche Agronomique, France |
| *Title* | Response to Robert Evans |
| *Speaker* | H te Molder |
| *Institution(s)* | Communication Science, Wageningen University, NL |
| *Title* | Response to Robert Evans |
| *Speaker* | E van Rijswoud |
| *Institution(s)* | Philosophy & Science Studies, Faculty of Science, Radboud University Nijmegen, NL |
| *Title* | Response to Robert Evans |

# SESSION V-F
# GENOMICS DISCOURSE

*Author(s)* M Döring & R Kollek
*Institution(s)* FSP BIOGUM / FG Medizin, University of Hamburg, Germany
*Title* **Constructing the Metabolic Syndrome: The Scientific Aetiology of a Disease Concept**

Research in the humanities and in sociology has mainly engaged with the field of 'new genetics'. Focussing on broader social implications and the social shaping of genetic technologies, patients' responses to medical genetics or perceptions of risk, research on biotechnological issues is still dominated by bioethics and legal theory. However, a tendency prevails in this type of research to take facts of genetic science as a given.
This paper takes a different angle as it suggests investigating the textual construction of medical knowledge as a relevant site of interest for sociologists and scientists in the humanities. It tries to address changing patterns of written knowledge production by showing how the emerging concept of the Metabolic Syndrome (MBS) has been constructed and shaped by prominent researchers in the field and by review articles. The analysis uses a discourse oriented approach in order to tackle different conceptualisations of the MBS and how they interact with competing theories that frame the MBS as a complex bundle of genetic and environmental factors. The main aim of the paper is to provide insights into the Aetiology of the MBS, understood here as the constructive process by which causes and origins are attributed to a syndrome which has not yet been classified as a disease. This type of research will become increasingly important in the future when established disease concepts will be replaced more and more by syndromes, conditions and disorders with different aetiologies (in the traditional and the novel sense of the word).

*Author(s)* W de Groot1 & R van den Born2
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2 Philosophy and Science Studies, Faculty of Science, Radboud University Nijmegen, NL
*Title* **The artificial body: an empirical exploration of lay ethics**

Much of the application of genomics will imply an artificialisation of the human body, more or less parallel to what human society does to nature. In landscapes, we see a long gradient from the purely artificial cities through the domesticated agricultural zone to the authentic wilderness. What do lay people think of technological interventions that would create the human body as a comparable mixture of the technological and the natural?
In 30 semi-structured interviews in the Netherlands we discussed (1) ethical principles on human interventions in nature and body, and (2) four series of exemplars of interventions in nature and body, with genetic interventions distinguished from non-genetic interventions and the exemplars arranged in order of depth of intervention (e.g. from plastic tooth to plastic body). The results reveal the richness of people's ethical reasoning and some differences between categories of respondents. Overall, people's ethical reasoning could be captured in a scheme of three areas: (a) an 'area of frivolous purpose', where interventions are rejected because they do not serve a fundamental aim, (b) an area of 'too deep, too far', where interventions are rejected because humans should not want to interfere with nature on that level, and (c) an area in between, where people follow a reasoning of broad cost-benefit analysis. If considered in that area, our exemplars tended to be positively evaluated.

*Author(s)* R Komduur, H te Molder & M Korthals
*Institution(s)* Applied Philosophy, Wageningen University, NL
*Title* **Prevention and Nutrigenomics: An analysis of talk on genetics, overweight and health risks**

Nutrigenomics promises to contribute to the prevention of diseases by calculating health risks of nutrients on the basis of insight into their interactions on a genome level. This knowledge can be used for dietary advice based on personal risk information, or risk information about groups, and the production of functional foods.

Up till now, ELSA research has mainly focused on the problematic consequences of nutrigenomics research. There is hardly any debate about the implicit assumption in nutrigenomics research that personal risk information will automatically motivate consumers to change their health related behaviour. Moreover, it is still unknown if, and if so, how the notions of genetic susceptibility and personal risk play a role in everyday talk.
This paper draws on discourse analysis to examine accounts of overweight and genetic determination in six group interviews. The role of genetic predisposition and family history in explanations of overweight and overweight related health risks were the main focus. Preliminary results show, firstly, that accounts focused on genes are used by participants 'in the last resort', and that they are offered and treated as requiring specific evidence. This suggests that the 'gene repertoire', while hard to undermine once it is coined, is at the same time interactionally problematic and risky. Secondly, whereas it does not lend itself for an easy explanation of one's own overweight, the gene repertoire is regularly drawn upon to manage blame and responsibility in relation to others.

# SESSION VI-A
# FUTURE USER PERSPECTIVES

*Author(s)* R Pin & J Gutteling
*Institution(s)* Behavioural Sciences, University of Twente, Enschede, NL
*Title* **Public perception of nutrigenomics - personalized nutrition and functional foods**

Nutrigenomics, the study of how foods interact with our genes, promises solutions in medicine and health, but will also have an impact on society. Various studies show that European citizens have second thoughts concerning applications of gene technology, especially related to food (Bauer, 2005; Gaskell, 2004). If genomics technology will be able to predict diseases and prescribe preventive diets based on a person's genes, it is important to understand the public's intention to adopt such personalised diets. The same goes for another application of nutrigenomics: the development of more and advanced functional foods, food products with an ingredient added to benefit the health. What is the public perception of risks and benefits of this emerging technology in the year 2007? In this study we conducted survey research among a representative sample in The Netherlands (n=2990) in October 2007. We will confront our panel members with statistics on the publics behavioural intention to adopt the two applications of nutrigenomics, the public perception of possible consequences of introducing personalised nutrition and functional foods, their general affective evaluation, benefit and risk perception, trust in legislation by the government, perceived knowledge, and exposure to media and popular culture covering this topic. Furthermore, we have explored the differences between public perception of both personalized diets, based on one's gene-structure, and functional foods.

*Author(s)* A Roelofsen & J Broerse
*Institution(s)* Athena Institute for Research on Innovation and Communication in Health and Life Sciences, Vrije Universiteit, Amsterdam, NL
*Title* **Future users as agenda setters for ecological genomics research**

The Ecogenomics Consortium (an innovative cluster, headed under the Netherlands Genomics Initiative) aims to develop practical tools for sustainable use of soil ecosystems for agricultural and other anthropogenic purposes. Involving potential future users in setting the agenda has been recognized as a promising approach to developing applications that address practical needs. Within the framework of the Ecogenomics Consortium we design, implement and evaluate an interactive approach in which the methodology of vision assessment is integrated. This approach aims at involving potential future users in agenda setting when scientific developments are still in a rather basic stage, and actual applications are lacking. As a first step in this approach members of the Ecogenomics Consortium articulated their visions of ecogenomics in the future.
In this presentation we reflect on the second step, which consisted of 11 focus groups with 75 potential future users of ecogenomics (e.g. focus groups with policy makers, farmers, bioremediation companies and hobbyist gardeners). The participants were challenged to reflect on the future visions of Consortium members from their own perspective and identify pitfalls and (additional) opportunities for ecogenomics in practice. As an example, they articulated pitfalls related to current policy, and the need for a shift in that area in order for ecogenomics to be implemented successfully. They also identified some additional focal points, which are currently not addressed within the Consortium. Furthermore, they emphasized the need for a strong link between the Consortium and societal actors, and expressed their interest in future involvement. As a next step, dialogue meetings are organized to integrate the visions on desirable futures for Ecogenomics and articulate strategies for realizing these futures. We discuss the implications of our results for this next step in the agenda setting process.

*Author(s)* B Wynne
*Institution(s)* ESRC CESAGen, Lancaster University, UK
*Title* **Public Science and Imagined Publics: Whose Agendas Might Be at Stake?**

# SESSION VI-B
# AGENDAS & POLITICS

*Author(s)* E Frow
*Institution(s)* ESRC Genomics Policy & Research Forum, University of Edinburgh, UK
*Title* **The Politics of Plants: Emerging issues for Plant Genomics and the Global Bioeconomy**

This paper proposes that plants provide an interesting lens through which to view several key policy and governance challenges facing the world today. Plants are a common thread running through issues including climate change, environmental health, food security, agricultural reform, and the transition towards a bio-based economy, and as such offer a productive focal point for identifying policy and regulatory inconsistencies, and for developing holistic and sustainable solutions. Thinking of plants as a renewable but finite resource can help to address the challenging question of how to reconcile the tension between growth, innovation and sustainability.

This position has been developed through an innovative work programme at the Genomics Forum. We have established a core group of senior natural scientists, social scientists and policymakers who meet and deliberate on a regular basis. The aim has been to identify and develop a conceptual framework that is seen to have shared relevance among these different stakeholder groups. Through a series of interdisciplinary meetings and workshops focused on different issues relating to plant genomics and the bio-based economy, we are attempting to define and map the 'politics of plants,' which we suggest is taking on new dimensions and significance as the bioeconomy develops.

This paper will use bioenergy as a case study to illustrate some of the tensions and questions central to the emerging politics of plants, and will relate the findings from this analysis to the wider framework being developed through this ongoing project.

*Author(s)* C van de Weele
*Institution(s)* Applied Philosophy, Wageningen University, NL
*Title* **Moral agendas for genomics: how to find blind spots?**

Several recent inventories of ELSA/ELSI- genomics research have revealed patterns and trends in the agendas. They also intended to identify blind spots, or what was missing from those agendas, but in this respect the results have been more haphazard. This paper aims to provide a method for finding blind spots.
Blind spots cannot easily be identified through empirical inventories; identifying what is missing requires a normative outlook on what should be there. Views of relations between science and society provide such normative outlooks. I describe three different and rivalling views of these relations, each of which determines a different agenda. Looking at their metaphorical and pictorial framing will help to understand their strengths and weaknesses. For example, the ELSI agenda is largely framed through the view that society builds on the results of scientific research, a metaphor that has been compellingly pictured as well. Alternative views are 1. that science and society co-evolve and 2. that science should be harnessed to address a predefined moral agenda. These alternative views are framed through metaphors as well, but the metaphors come with less compelling pictures. I will discuss the significance of this finding.
In the search for blind spots in moral agendas, the three frames should not just be seen as rivals. In the absence of an absolute normative frame, blind spots in each frame-dependent agenda can be found from the point of view of the other two. I thus argue that from a moral point of view we should actively embrace multiple normative perspectives. Given that one frame is now dominant in shaping moral agendas, this implies that the two other frames, especially the third one, need to be empowered.

*Author(s)* H Harbers & M Huijer
*Institution(s)* Department of Philosophy, Groningen University, NL
*Title* **The time-politics of genomics What about the political and policy relevance of ELSA-projects?**

In our research project Gene-Time: Genomics and the Construction of Time (funded by Netherlands Organization for Scientific Research, subprogram "The Societal Component of Genomics Research", projectno. 050-32-002), we have studied the implications of genomics in terms of changing perceptions and institutionalizations of time. What new ways of 'being-in-time' has genomics induced? In the context of biomedicine, for example, prenatal DNA-tests create the illusion that all potential futures can be identified in the present. Conversely, the use of genomic techniques in legal contexts displaces the past into the present: since DNA tests make it possible to reopen old cases, statutory periods of limitation have been extended or completely abolished. Thus, genomics inserts the future and past into the present.

Compared to other ELSA-projects in genomics, our project was initially received as rather vague, abstract, philosophical, and thus policy irrelevant. Later on, however, the project was embraced as highly relevant. It has put morally and politically urgent questions on the agenda, such as: Does the accumulation of genetic information overburden the present? Is it really possible to know and control the future? Are we loosing the capacity to forgive and forget, and leave the past at rest? Questions like these refer to new, genomically induced, cultural practices and frames of meaning. They require public discussion and political imagination, and are more than a short-cut to the usual policy-instruments.

In our view, both appreciations of the project were right: the project was politically relevant just because it tried to figure out relevant issues, instead of following existing policy-agenda's. In a context of new and uncertain scientific and technological developments like genomics, what relevant policy-questions are is in itself an urgent, politically relevant question.

# SESSION VI-C
# GENOMICS REGULATION

*Author(s)* D Wilson-Kovacs, S Weber & C Hauskeller
*Institution(s)* ESRC Centre for Genomics in Society, University of Exeter, UK
*Title* **Stem Cell Research Agendas: Regulation as Culture in Practice**

Since 1998 stem cell research has been established as a field of scientific inquiry that has raised much controversy being conceived as a greatly promising endeavour in the treatment of degenerative diseases on the one hand; and on the other hand being subjected to ethical debates, especially regarding the use of embryos in research. Within the EU, this has made for intersecting yet distinct national pathways, which have been the basis of much scholarly discussions on governance and science policy.

However, little attention has been paid to the impact of these varying regulatory regimes on everyday scientific practice. Here we address this gap and propose an understanding of regulation as upstream interactional accomplishment between researchers, clinicians and regulators. We present findings from our ethnographic fieldwork in laboratories and clinics involved in stem cell research in Britain and Germany, and examine the role of regulatory practices in their operations. The analysis seeks to answer the following: How is the organisation of scientific and clinical activity involving stem cells affected by regulation? What are the differences and similarities in attitudes to regulation between British and German labs and clinics? How do those working with stem cells make sense of the regulation? How do actors reflect on the intersection between governance and scientific development? What are the implications for policy makers?

We focus on the ways in which the regulation of research and clinical practices is mediated by distinct divisions of labour that structure how science is done. We also highlight the need to scrutinise the bodies of practices and networks of interactions, interests and expertise created through regulation, in order to give a rich account of and assess the effects it has on scientific development.

*Author(s)* A Roosendaal
*Institution(s)* Tilburg Institute for Law, Technology, and Society (TILT), Tilburg University, NL
*Title* **When Patent Offices Become Ethical Committees. Human embryonic stem cell patents and morality clauses**

The European Patent Office (EPO) has to decide on the patentability of human embryonic stem cells (for example in the pending WARF-case). However, problems arise with regard to the interpretation and application of morality clauses as included in the European Patent Convention and Directive 98/44/EC on the protection of biotechnological inventions. In essence, the debate concentrates around the question whether the EPO has to take morality into account when deciding on the patentability of certain inventions. A clear answer, however, is difficult, or even impossible, to define, due to the fundamental character of the issues at stake. As a result of this fundamental character, proponents as well as opponents are using arguments with a wide range of (theoretical) backgrounds (ethics, politics, and religion).

In order to come to a workable solution, this paper proposes a procedural approach. Criteria for the application procedure and the decision making process should provide a proper basis for acceptance of the decisions of the EPO by all parties involved. Main criteria are transparency of the procedure, openness on the criteria which are being used, and the possibility to correct decisions.

Next to these criteria, other options to deal with moral considerations in patent application procedures will be touched upon. The aim of the paper is to come to a guideline with general indications on how to deal with morality in practice with regard to human embryonic stem cell patents.

*Author(s)* M Li
*Institution(s)* Department of Sociology, Edinburgh University, UK
*Title* **To See the World in a Grain of Rice: Contesting the Commercialisation of GM Rice in China**

The commercialisation of GM rice in China claims a strategic role in the international battle between the pro-GM and GM-critical camps as are chaired by the US and EU countries. This decision also relates to the most important staple food for 1.3 billion Chinese people, and is of massive impact at home. Despite the governmental initiatives and heavy investments in parenting biotechnology and the breakthroughs of independent scientific research on rice genome, the decision to commercialise GM rice has been pending for already seven years. What could have caused the policy delay registers a big question mark for all parties concerned.

My paper will explore, describe, and explain the meanings and practices associated with GMO risk within the scientific communities, policy circles and public arenas, characterise the relevant social/political milieu, and analyse the interests that could have contributed to the shaping of these meanings and practices. Knowledge, power and interests regarding the GMO safety issue constitute the locus of the research, which must be understood in relation to decision-making under the backdrop of rising public awareness and intervention of the policy process, a novel phenomenon in China.

Greenpeace entered China in 2004 as the first international pressure group whose strategic campaigning on selected issues, through increased media coverage, are mapped into the pre-existing hierarchy of news values, thus specific environmental problems gained social saliency. In the case of GM rice, Greenpeace has successfully wielded the power of what Stuart Hall termed as the 'primary definer' - "who initiates the primary interpretation of the issue… (which) then commands the field in all subsequent treatment and sets the terms of reference within which further coverage of debates takes place' (Hall, 1978) . The rise of the new environmental risk discourse in China signifies a radical departure towards 'reflexive modernization' (Giddens, Beck, Lash, 1994); and I argue that the government's tolerance and encouragement of public participation in monitoring environmental administration reflect the deeper agenda of the Chinese government whose institutions start to adopt self-confrontational, critical engagement with the downside of the linear logic of economic development.

# SESSION VI-D
# ANYTHING NEW?

*Author(s)* B Prainsack
*Institution(s)* Centre for Biomedicine & Society (CBAS), King's College London, UK
*Title* The Emperor's Old Clothes: Examining the 'bio' in 'sociality'

It has often been argued that knowledge and technologies of the New Genetics and Genomics have deeply affected individual and collective identities. The emergence of concepts such as somatic selfhood (Nikolas Rose), biosociality (Paul Rabinow), geneticization (Abby Lippman), and biological/genetic citizenship in the social science literature demonstrate the conviction that understandings of ourselves and our position in society are increasingly being penetrated by biological and genetic definitions.

While genetic and genomic knowledges and technologies have certainly had a significant impact on how we regard our bodies in the medical realm, it is still unclear to what extent they have indeed changed individual and collective identities. As Featherstone et al (2005) have pointed out, rather than establishing new notions of identities and kinships, New Genetics and Genomics knowledges have been assimilated into existing notions of selfhood and belonging.

On the occasion of two empirical case studies, I will discuss particular ways in which genetic/genomic knowledges enter existing concepts of selfhood, identity, and kinship. Moreover, I will argue that these knowledges often do not modify but rather reinforce and deepen pre-existing concepts and identities. My first example will draw upon 26 in-depth interviews on the topic of forensic DNA profiling and databasing carried out in Austrian prisons in 2006-07.
My second case study (2006-2008) discusses how 50 female identical vs. non-identical twins use observations about their bodies in the context of sexual activities to reinforce their particular identities as identical or non-identical twins respectively.

*Author(s)* J Goven
*Institution(s)* Centre for Integrated Research in Biosafety,
University of Canterbury, Christchurch, New Zealand
*Title* Shaping the ELSA agenda: new technologies and old politics

Implicated in the question of whether and how ELSA research shapes agendas in genomics research, practice, policy and public debate is the question: what is—and what should be—on the ELSA agenda? Has ELSA paid enough attention to the "old politics" shaping and receiving the "new technologies"? Has a fascination with the new actors, networks and practices seen as characterising genomics governance diverted us from giving due attention to the role of existing institutions? This paper uses the findings of research into genetic testing, nutrigenomics and biopharming to highlight the importance of existing social and political institutions for understanding the implications of genomics. It argues that the some of the most significant potential negative implications cannot be addressed without addressing longer-standing issues of the distribution of power within and modes of operation of existing social and political institutions. This has implications for the question of whose agenda ELSA research should be aiming to influence.



*Author(s)* P Stegmaier
*Institution(s)* Philosophy and Science Studies, Faculty of Science, Radboud University, Nijmegen, NL
*Title* Doing Society and Genomics

New regimes of public participation and social scientific research accompanying large scale genomics and life-sciences projects have begun to change the relationship between sciences and society in some, but by far not all Western countries. Since 2002 three research centres of the ESRC Genomics Network (EGN) have been formed in the United Kingdom and in 2004 the ESRC Genomics Policy and Research Forum has been added, and also since 2004 the Centre for Society and Genomics (CSG) in the Netherlands has taken up its work. Both initiatives are now in the second phase of ample funding. In general, these initiatives share ambitions to be relevant to democratic policy making processes and to foster collaboration between natural and social sciences.
The question is what characterises their modes of operation in practice. Drawing from interviews and observations built up in an ongoing empirical study, this paper sketches what it means to engage in research and debate upon genomics in society for those doing it. In order to grasp this particular mode, I propose to speak of "doing society and genomics".
There are differences in their cultures, activities, histories, foundations, and institutional contexts. They differ e.g. in the combinations of disciplines involved, in weight and direction which the stimulation of societal debate has got, the way stakeholder involvement is rooted in national traditions of negotiating conflictive opinions, how the centres are organised internally, and how the processes and structures of funding are set up. Also the top down notion "ELSA" (the European variant of U.S. "ELSI") is not used very lightly or is even avoided, although in some places some effort goes into building up a more or less coherent "scene" or "community" related to the ELSA idea. The paper focuses on circumstances for such paradoxical self-identification and professional affiliation.
Further on, I suggest that "doing society and genomics" not only applies for social scientists and philosophers at the aforementioned centres and networks, but also for life-scientists who for any reason communicate their research beyond the laboratory doors. To a certain extent, social and natural scientists get practically involved instead of conceding the field e.g. to "external" technology assessment organisations. This is one key feature of a new interactive mode of doing science and of science governance today, which cannot be reduced to a new mode of knowledge production. Produced is across the sciences' divide also attention for issues, new institutional procedures, and legitimations.

## SESSION VI-E

# INTERNATIONAL DECLARATIONS ON BIOETHICS: AN ASSESSMENT "FROM WITHIN"

*Session organiser* **H Zwart**

In an era of globalisation, the technosciences, notably genomics, are quickly evolving into a worldwide, global phenomenon (Thacker 2005, Rose 2007). The question inevitably emerges whether and to what extent bioethics can and should become a globalised phenomenon as well. Could we somehow articulate a set of core principles or values that ought to be respected worldwide and could serve as a universal guide for bioethical regulations and for embedding biotechnologies in various countries? International organisations (notably UNESCO, an intergovernmental organization officially mandated by member countries to issue standards, and the HUGO ethics committee) already play a prominent role in this respect. Their objective is to contribute to the process of agenda setting for debate and policy development concerning genomics.

UNESCO declarations on genomics ("The Human Genome and Human Rights", "Declaration on Bioethics and Human Rights") are examples of such efforts. The HUGO ethics committee, as an international platform, has published a series of statements on core issues in the genomics ELSA domain, including DNA Sampling (1998), Cloning (1999), Benefit Sharing (2000), Gene Therapy Research (2001), Human Genomic Databases (2002), Stem Cell Research (2004) and Pharmacogenomics (2007).

However, the usefulness and legitimacy of this type of documents is a matter of dispute. Bioethics as it has evolved in recent decades is regarded by many as a "Western" phenomenon, in terms of core concepts (autonomy, informed consent, privacy) and of historical backdrop (Enlightenment, the eugenics experience, experimentation with prisoners during WWII etc.). It cannot be regarded as an "export product". Rather, the process of building a global bioethics should assume the form of an international trans-cultural dialogue, as the emergence of globalising biotechnologies will meet with different responses in various cultural realms, on the basis of different sets of values. How may these various responses contribute to a global bioethics?

In an editorial to a special issue of Developing World Bioethics, a UNESCO declarations has been criticized, arguing that the "values claimed to be universal in this document" (such as "human rights" and "dignity") are not that universal and that UNESCO is actually trespassing on the domain of professional bioethicists.

Question: how are these declarations produced (in terms of methodology and international involvement)? What impact do they have internationally in terms of agenda setting for debate and genomics governance? How do they function in terms of embedding bioethics in research policies concerning genomics and related fields worldwide, notably in non-western countries? What are the main items of contestation, not so much in terms of conceptual issues, but rather in terms of implementation and genomics governance?



Methodologically, the session constitutes a form of "self-reflection", a critical assessment of personal experiences with efforts devoted to the globalisation of Bioethics through declarations and implementation initiatives. All speakers invited have some experience and involvement (either structurally or ad hoc) with the process of developing and implementing the type of declarations mentioned.

*Author(s)* **R Chadwick**
*Institution(s)* **CESAGen, Cardiff University, UK**
**HUGO Ethics Committee, London, UK**
*Title* **Statements by the HUGO ethics committee: a reflection**

The paper reflects on the methodology and impact of HUGO ethics statements. How where these statements produced? What learning processes were involved? Notably, the focus will be on the question how the issue of globalisation was addressed. How were responses, challenges and criticisms in terms of the global outreach of these statements taken up and addressed? What is the impact of these statements beyond the western world? (Ruth Chadwick is director of CESAGen, UK)

*Author(s)* **M Levitt**
*Institution(s)* **Department of Philosophy, Lancaster University, UK**
*Title* **Globalising bioethics: a case study (1)**

The paper reflects on reactions to the UNESCO declaration on genomics mentioned above in order to discuss criteria by which such declarations could be assessed. Important focus is the methodology of producing the declaration (notably efforts to ensure that core principles are recognisable and applicable worldwide) as well as the criticism that the declaration is lacking in attention to the social / cultural context of bioethical.

*Author(s)* **H Zwart**
*Institution(s)* **Centre for Society & Genomics, Faculty of Science, Radboud University Nijmegen, NL**
*Title* **Globalising bioethics: a case study (2)**

The paper reflects on experiences of a UNESCO delegation that visited Yakutia (Siberia) in 2005 to assess a genetic screening program for myotonic dystrophy and to establish an ethics committee for future monitoring of this program and for developing a policy.

*Author(s)* **D Macer**
*Institution(s)* **ao HUGO Ethics Committee, UNESCO**
*Title* **Response to presentations**

Darryl Macer (invited speaker) has agreed to respond to these presentations and open the discussion.

*Author(s)* F Börner
*Institution(s)* Program Group Human, Environment & Technology, Institute for Neuroscience and Biophysics, Research Center Jülich, Germany
*Title* **Framing effects on lay risk and benefit evaluations of toxicogenomics**

Toxicogenomics is a technology with a great potential in risk assessment and public health. A promising field of application is the early detection of susceptible individuals who might be at risk from a particular environmental hazard or susceptible to side effects of drugs. However, the application of toxicogenomics technologies may not only yield great benefits but also risks, for instance with regard to privacy information and other ethical considerations. Thus, the public acceptance of new genomics applications such as toxicogenomics technologies may depend on how risks and benefits are perceived. Research has shown that such evaluations are often fragile, depending on how a technology is framed with regard to risk and benefits or context factors such as field of application.

We investigated in an experimental study whether the evaluation of toxicogenomics technologies was influenced by such contextual factors. We used a 2 x 2 factorial design. Factor 1 was a field of application frame (diagnosis vs. therapy); factor 2 was a beneficiary frame (industry vs. regulatory agencies). Risk, benefit and risk-benefit evaluations were measure by 5-point Likert scales. We also investigated whether the evaluation of toxicogenomics technologies was different when implicit measures were used. Explicit measures, such as Likert scales, differ from implicit measures in that the latter are actions or judgments that are under the control of automatically activated evaluation, without the performer's awareness of that causation. The Implicit Association Test (IAT) was used for measuring implicit evaluations. IAT measures are based on response latencies of automatic positive-negative evaluations.

The study was conducted at a science fair where visitors (N = 54) participated in a computer supported experiment. Subjects read vignettes which described the potential of toxicogenomics for the early detection of susceptibility in a diagnostic or therapeutic context. The vignettes also included a paragraph informing about who would benefit most, industry or regulatory agencies. Subsequent, subjects answered three explicit risk and benefit questions using the Likert scales before going through the IAT.

With regard to the explicit risk evaluations, results show a significant main effect for the first experimental factor (field of application). Risk judgments were statistically significant higher in the diagnosis than in the therapy condition (M=3.30 vs. M=2.44). No statistically significant differences were found for the second factor (beneficiaries: industry vs. regulatory agencies). For explicit benefit evaluations no significant effects were found for both factors.
With regard to explicit risk-benefit evaluation the experiment found a statistically significant main effect for the first factor (diagnosis M=2.93; therapy M=3.65), but none for the second. The implicit evaluation measured with the IAT showed no significant effect for both factors.



The results will be discussed regarding potential reasons for framing effects on different risk and benefit judgments as well as for the differences between explicit and implicit evaluations.

*Author(s)* S Evans
*Institution(s)* Innovation, Knowledge and Organisation Networks Research Centre, Warwick Business School, University of Warwick, Coventry, UK
*Title* **Exceptionally different? The requisite of special governance measures for the novel clinical utility of molecularised hereditary information.**

This paper uses interview data with practitioners about the clinical use of hereditary information within breast cancer and hyperlipidaemia clinics to empirically examine the notion of 'genetic exceptionalism'. The concept that genetic information is regarded as qualitatively different from other medical information as it intrinsically raises unique ethical, legal and social issues, results in an assumption that special ethical protections are necessary for the successful integration of genetic testing into clinical practice. The interviewees perceived a requirement for special governance measures, such as genetic counselling and informed consent. In addition, the disease-trained practitioners expressed a need for the principal management of the genetic testing of patients to be conducted by practitioners with specific expertise in clinical genetics. In contrast, the disease-trained practitioners were comfortable with directly handling more traditional forms of 'genetic' information, such as family history and blood-cholesterol data. However, although there was an overall perception that the clinical use of molecular genetic information required special management, this paper argues that this is not because this type of medical data is 'exceptionally different'. Instead, it is proposed that for molecular genetic data to become successfully established into clinical usage, it must provide a clinical utility that is constructed as novel compared with the established clinical practice. This results in a need for special governance measures and clinical processes because this new type of medical knowledge prompts a 'paradigm shift' (Friedman-Ross, 2001) in the form of a new and different approach to the clinical management of patients. Therefore, it is argued that over time the use of molecular genetic information will gradually become reconstructed from being conceptualised as especially different, as this type of clinical practice becomes 'normalised'.

*Author(s)* S Fennell
*Institution(s)* TILT - Tilburg Institute for Law, Technology and Society, Tilburg University, NL
*Title* **ICT regulation as the foundation for biobanking regulation?**

The last few years have witnessed the rise of large bio repositories or biobanks, databases filled with human materials such as tissue samples and DNA, and additional information regarding these materials. Currently, efforts are being made to develop many large biobanks. Countries like the US, the UK, Iceland and Estonia are building large databases for medical research both public and private. Obviously, these developments raise concerns on various levels; ethical, legal, economical and political. These concerns include among other con-

cerns regarding privacy, discriminatory selection, unjustified discrimination, classification and commercialisation of human materials. Solving these problems requires swift policy and regulatory measures. The paper will focus on the possibilities to solve problems in the field of biobanking with the help of solutions found in ICT research. In-depth exploration of the possibilities to combine insights of ICT regulation with biotechnology can result in solutions for both research areas.

*Author(s)* B Green
*Institution(s)* Department of Sociology and Philosophy, University of Exeter, UK
*Title* **Being there and learning there: expertise and alignment in laboratory research**

Whether occupying the same institutional space or neighbouring spaces, the process of bidirectional stimulation between ELSI and genomics research is a complex one. Where this involves ethnographic fieldwork, scientists and ELSI researchers stand side-by-side at the bench, ostensibly following their own objects and disciplinary programmes. However, a self-reflexive approach to the experience of observational research can reveal symbiosis within the relationship grounded in local interaction. For ELSI research, this can be captured by the (re)description of specific projects in terms of their 'doability' (Fujimura, 1987). In the context of an observational study of a molecular biology laboratory, the identification of processes of alignment highlights how ELSI and genomics research interact and undergo mutual realignments in relation to local exigencies. Where this involves the creation of new international expertises within and between disciplines, the recognition of a symbiotic relationship impacts upon the practice, process and products of research in both spheres.

*Author(s)* J Jacobs
*Institution(s)* META, Wageningen University, NL
*Title* **A public-private invitation: genomic research and agri-food chains**

The agro-sector in the Netherlands is a dynamic area. The ecological, economical, international and societal claims demand a shift in the boundaries of this sector. To cope with al these changes genomics research may help. One of the Dutch centers in this field is the Centre for BioSystems Genomics (CBSG). It's the intention that the participating companies take advantage of the new genomics knowledge and that a knowledge flow starts in the direction of farmers, industry, retailers and consumers. Does it work? Is the knowledge flow as best as possible? These are central questions in CBSG research project 'plant genomics and interactive food supply chain management within the potato-and tomato chain'. During an Invitational Conference researchers and other chain parties of the potato- and tomato chains have met each other. These people were discussing fine tuning between genomics research and the wishes and interests of chain parties. It can be concluded, for example, that the difference between the potato and tomato food chain lies in consumer orientation. In contrast to the tomato chain, which is fully consumer oriented, the potato food chain is a producers chain. Although genomics research could change this situation, this is not expected because of the high investments.



*Author(s)* R Johnstone
*Institution(s)* University of Sydney, Australia
*Title* **Essentially Yours: Australia as a case study in the development of public policy relating to genomics**

Australia provides a useful case study on the development of public policy relating to genomics.

This paper looks at three phases of the development of regulation of genetic information in Australia, using each as an opportunity to critically examine the influence of genomics research, political parties and other external influences on each of those stages.

This paper starts by examining the genomics research and policy environment of the early 1990s.

It then moves to the Australian Law Reform Commission report delivered in 2003. This report made 144 recommendations covering information privacy, protection against unfair discrimination in employment and insurance, the use of genetic information in forensic investigations and parentage testing and ensuring the highest ethical standards in medical research and practice.

Finally, it examines the impact of the report and the current state of regulation, assessing the extent to which genomics research has set or followed the setting of priorities for reform.

*Author(s)* M Kato
*Institution(s)* International Institute for Asian Studies, Leiden University, NL
*Title* **Reproductive genetic technologies and emerging challenges to medical professional identity: a case of Japan**

Patients often believe that doctors can confidently lead them to good medical decisions, believing that doctors are almighty in their field. This is because doctors have knowledge and command in technologies, which patients do not have. A closer look at medical practices shows, however, how medical doctors are trying to cope with the rapid speed of the development of technologies such as nuchal translucency. Although NT is not a new technique, the more sophisticated the ultrasound apparatus becomes, the more skill is required to handle it, which not all doctors can master. Yet doctors cannot stop using ultrasound because it is part of routine practices during pregnancy.
This presentation looks at how increasingly sophisticated techniques of reproductive genetic technologies – NT in this case – bring about 'new' problems among medical professionals, even threatening their identity, and how these new problems are eventually influencing patients' decision-making practices as well. The analysis of this presentation is based on narratives of doctors and patients, being contextualized in the Japanese setting of medical services.

*Author(s)* L Landeweerd
*Institution(s)* Kluyver Centre for Genomics of Industrial Fermentation & Department of Biotechnology, Biotechnology & Society Group, Delft Technical University, NL
*Title* **Stakeholder Communication and Biofuels**

Biofuels, produced with the help of genetically manipulated yeasts (the so called second generation biofuels) are a possible alternative to fossilized fuels. However, the support for the introduction of biofuels is varied, often resulting in the failure of dialogue between stakeholders. We are conducting an ELSI-based stakeholder analysis to follow the rationale behind the different decisions that were made regarding the implementation of biofuels. However, it is important to acknowledge that the opinions held by different stakeholders are not merely influenced by facts alone, but also by the different belief systems they stem from. However, this counts for the scientists and technologists as well as ourselves, since the Kluyver Centre for Genomics of Industrial Fermentation is active in studying production methods for second generation biofuels. Being a stakeholder ourselves might affect the neutrality of our stakeholder research. How to avoid this, if possible, and if not, how to make it explicit in such a fashion that we can at least host an open debate about biofuels?

*Author(s)* U Naue
*Institution(s)* Life Science Governance Research Platform, Department of Political Science, University of Vienna, Austria
*Title* **Attitudes towards genomics in Alzheimer's disease research and intervention**

About one hundred years ago, Alois Alzheimer described Alzheimer's disease (AD) for the first time. When presenting the data of his first patient at a conference, nearly nobody took notice of his presentation. At that time, medical science showed no interest in this disease. But during the last decades, this situation has changed dramatically. Due to a growing greying society, AD is increasingly perceived as a global threat and widespread disease of the elderly. Nowadays, AD is not only a subject of medical intervention, but also an important target of socio-political action. Along with the increasing medical and socio-political interest in AD, various public perceptions of this disease have evolved. Patients, policy makers, health care professionals and basic researchers may demonstrate diverse, changing and to an extent divergent attitudes towards AD. For example, the shift in basic research from the brain to the genes over the last years has marked a substantial change in how AD is approached. Anecdotal evidence suggests that whereas clinician attitudes towards AD genomics may at times be negative and dismissive, patients, media and policy makers often feel encouraged by the prospect of genetic research in finding a cure and treatment for AD. While popular support has a positive effect on basic genomics research into AD, its impact on current health care practice and health interventions is more complex. In denying the relevance of genomics research for their practice, health care professionals often act in opposition to patients' hopes in genomics. The aim of the presentation is to identify and describe attitudes toward genetic research in AD from the perspective of various key stakeholders. We will report on results from in-depth interviews with health care professionals and researchers and findings from a rapid evidence review of relevant literature using multiple electronic databases (e.g. MEDLINE, CINAHL, AGELINE, Cochrane, PsycINFO). Findings are discussed in terms of their relevance for research and intervention practices.



*Author(s)* V Pavone
*Institution(s)* Institute for Public Goods and Policies, CSIC, Madrid, Spain
*Title* **Genetic testing, geneticization and social change; Insights from genetic experts in Spain**

Drawing inspiration from some pioneer studies on biomedicalisation and geneticization, this paper conducts an exploratory analysis of some of the social and political challenges that the diffusion of genetic testing technologies (GTTs) increasingly poses to the current policies of biomedical innovation and healthcare. Drawing on a series of semi-structured interviews with experts in genetics, the paper specifically explores the Spanish context. The outcomes of the analysis seem to suggest that GTTs are playing a crucial role in the complex interaction between biomedicalisation and geneticization. Fuelling on the rapid increase of health expenditure, GTTs also seem to encourage the emergence of new health care policies, based on an individualistic and consumeristic conception of health, disease and healthcare. Although the clinical practice has been so far almost unaffected, the research agenda seems to be increasingly shaped by a narrow approach to common diseases, focusing on genetic predispositions whilst neglecting social and environmental factors. Although we haven't found any evidence of existing genetic discrimination practices, the possibility that a wrong social perception and use of genetic information may give rise to discrimination in insurance and employment cannot be entirely ruled out. In contrast, the diffusion of pre-natal and pre-implantation genetic testing is actually endorsing so called 'weak eugenics' processes that are gradually shifting the emphasis from primary to secondary prevention. These results urge current systems of genetic technology regulation, generally focusing on bioethical or technical considerations, to broaden the dominant cognitive approach with new insights from empirical studies on the social and political implications of a large-scale implementation of the new biomedical technologies.

*Author(s)* B Penders
*Institution(s)* Department of Health, Ethics & Society, Faculty of Health, Medicine and Life Sciences, Maastricht University, NL
*Title* **The silent de-elsification of European Nutrigenomics Research?**

Some ELSI research programmes exist next to the genomics research programmes, operating relatively independent from it and 'merely' treating genomics as an object of study. Other ELSI programmes are part of larger genomic networks, thus part of their own object of study. The European Nutrigenomics Organisation had institutionalized ELSI research and communication alongside genomic science in a number of 'work-packages'. Over time, as the programme matured and advanced, the work-package 'nutrigenomics & society' was merged with the 'science communication' work-package into the new work-package 'communications'. How and why did this organisational shift occur? What can we learn by com-

paring the role of ELSI research as separated, 'autonomous' sections in or aside large-scale science projects with ELSI research which has been driven to become an intrinsic part of large-scale nutrigenomics projects?


*Author(s)* I Petersen
*Institution(s)* BIOGUM / FG Medizin, University of Hamburg, Germany

*Title* **Disclosure and Confidentiality in Clinico-Genomic Research: Patients' Attitudes and Perspectives towards Individual Donor Feedback**

In clinico-genomic cancer trials data are collected and processed to identify genetic components which are involved in cancer development and reaction to cancer treatment. Though genetic factors are involved in the development and course of disease and a person's reaction to treatment, they do not cause them in the narrow sense of the term. Therefore, the clinical relevance of research findings is not easy to approach. Genetic information may – but may not necessarily – have indirect or direct diagnostic or therapeutic relevance for the patient's treatment.
Ethically, it is widely accepted that the research subject must be enabled to get information if a research process yields information that helps to avoid sickness or adverse drug reactions. But what about genetic information having only the potential to be clinically relevant?
Should these study findings that are often not easily comprehensible for lay persons be fed back to patients involved in clinico-genomic trials? Up to now, this question has only marginally and rarely explicitly been treated in ethical and legal discussions on clinico-genomic research and
no legal regulations in the US or the EU define requirements for such feedback. Therefore, we want to present an empirical survey regarding patients' attitudes and perspectives towards individual donor feedback and data protection we are preparing right now at the University of
Hamburg in the context of the EU-project ACGT (Advancing Clinico Genomic Trials on Cancer). What do the patients involved want? What kinds of risks and benefits do they anticipate concerning individualized feedback? What do they think about data protection in general?


*Author(s)* M Veen
*Institution(s)* META, Wageningen University, NL

*Title* **The impact of genomics on the everyday life of Celiac Disease patients**

Developments in human and food genomics will have an impact on the everyday life of Celiac Disease patients. What exactly those developments will be is unsure, but possible innovations include new screening methods and novel therapies. This paper examines what innovations are to be expected from genomics research, and which approach is most suited to allow celiac disease patients to integrate these new technologies into their everyday life. The impact of these future technologies themselves cannot be investigated since they have not yet arrived. Therefore it is important to examine as soon as possible important issues of celiac disease patients with respect to current diagnosis and therapy. For an important part, domestication of new technologies depends on the extent to which the developers take into account the everyday practices that patients are already accustomed to for dealing with the issues that these new technologies address.

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## Oral Presentations



## Posters