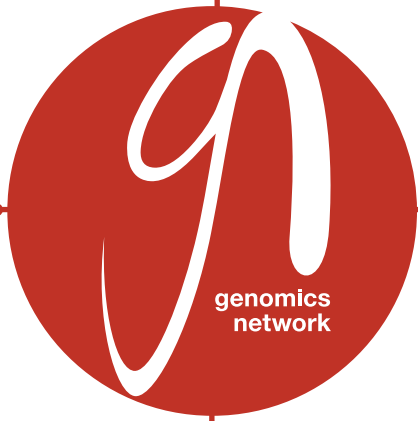


MARCH 11



the gen

The Newsletter of the ESRC Genomics Network – issue 13



BIODIGITAL FUTURES

**Pushing the
Boundaries
at Innogen**

**The Social
Science of the
Genome**

**onCore UK:
The £4m
Cancer Tissue
Bank that
Closed**

**The Human
Face of
Data-Intensive
Biology**



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21 The £4m Cancer Tissue Bank that Closed

Welcome

to the Spring 2011 issue of the gen. As we look forward to brighter and warmer days ahead we invite you to explore the current work of the Genomics Network.

We welcome your comments and ideas on our newsletter and invite you to contact us at: info@genomicsnetwork.ac.uk or **Genomics Network Newsletter, ESRC Genomics Policy and Research Forum, University of Edinburgh, St John's Land, Holyrood Road, Edinburgh, EH8 8AQ.**

The ESRC Genomics Network Newsletter is free and published twice a year. To receive your own electronic or print copy please contact: info@genomicsnetwork.ac.uk

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Insuring a rewarding placement

An ESRC Student Internship with Lloyd's of London allowed Innogen's Heather Lowrie to apply learning from her PhD on emerging risks in the insurance industry. She spent three months investigating how decisions are made in property and casualty underwriting.

During her placement, Heather secured industry support for a follow-on collaborative project with Lloyd's and several market participants to advance understanding of knowledge and governance of emerging risks in the insurance industry. The project aims to generate impact on research and practice through knowledge exchange.

"This placement was a great opportunity to develop ideas for my PhD and to generate impact on practice", said Heather.

For more on Heather's work visit: <http://bit.ly/hQ606g>

Long-term view on biological research

A paper co-authored by Egenis Research Fellow Sabina Leonelli assessed as 'dire' the funding situation for databases across biology, and proposed several business models to deal with long-term sustainability of these resources.

'Sustainable digital infrastructure' by Dr Leonelli and Ruth Bastow of the University of Warwick, was published in *EMBO Reports*.

"The past decade has seen an unprecedented explosion of data, tools and databank resources in the biological sciences," say the authors. "Access to online data has become a basic requirement for conducting scientific research", but they conclude, "a single, viable framework for sustainable and long-term stewardship of data and resources has not emerged."

"No current model is able to meet the requirements of cyberinfrastructure and data-intensive research," explains Dr Leonelli. "Sustained funding is needed to ensure that reliable and ready-to-use data can be found in high quality and up-to-date databases maintained by professional curators."

The authors argue that funding agencies and national governments operate under an outdated assumption that cyberinfrastructure can be treated either as another branch of the research process – the value and novelty of which needs to be constantly assessed and demonstrated – or as an inexpensive service that can be outsourced to industry or users themselves.

For further details visit: <http://bit.ly/cp4YS9>

International impact of Cesagen research

During 2010, the International impact of a Cesagen research programme, that has been developing over the last 10 years was realised when Dr Paul Oldham participated in the final negotiations of the Nagoya Protocol on Access to Genetic Resources and Benefit-Sharing at COP10 of the Convention on Biological Diversity in October.

The new protocol sets out an agreement on the terms of access to genetic resources and traditional knowledge in countries around the world, and the conditions of benefit-sharing. The protocol is intended to address the problem of 'biopiracy' of potentially valuable genetic resources from biodiversity rich countries and indigenous peoples and local communities. The protocol will also establish a global benefit-sharing fund for genetic resources.

In future work, Cesagen will examine ways to support implementation of the new protocol through its investments in digital methods and exploring the creation of accessible digital tools to track and monitor the use of genetic resources.

For further information please visit: <http://bit.ly/eSpzZg>

Forging ahead

The **EGN Genetics and Society Book Series** will be publishing five exciting new books over the course of 2011. Biomedicine is one of the primary areas covered by the Series, and these titles reflect the increasing diversity of social science approaches to genetics and related biosciences. Featherstone and Atkinson's *Making of a Syndrome* provide a rich exploration of the processes by which Rett Syndrome has been reconfigured as a genetic disease. In *Genetic Testing*, Arribas-Allyon, Sarangi and Clarke draw out the complex interplay between the discourses of autonomy, responsibility and blame within a range of settings from clinic, to internet, to media. Reed's *Gender and Genetics* offers a unique analysis of the role of men and the gendered nature of prenatal genetic screening. In the *Scientific, Clinical and Commercial Development of the Stem Cell*, Kraft looks at the past, present and future of the stem cell and its iconic role in the formation of biomedicine. Finally, moving away from biomedicine, *Barcoding Nature* by Waterton, Ellis and Wynne, documents new configurations between the knowledge cultures and practices of the taxonomic, biodiversity and computing sciences in relation to genomics.

For further details visit publications at: www.genomicsnetwork.ac.uk

Evidence of gender bias in diagnosing autism

Egenis researcher Ginny Russell published a paper in the journal *Social Psychiatry and Psychiatric Epidemiology*. The study, 'Social and demographic factors that influence the diagnosis of autistic spectrum disorders', conducted with colleagues from the University of Bristol, found that boys were significantly more likely to receive a diagnosis of autistic spectrum disorder (ASD) than girls, even when symptoms were equally severe.

The researchers examined data from a long-term study, the Avon Longitudinal Study of Parents and Children. "We thought that there may be social and demographic factors that explain why some children with autistic traits are diagnosed and others are not. Understanding social factors that act as access barriers may provide useful insights for clinicians in practice," Ginny explained.

"Boys are more than four times more likely to have ASD and are clearly more likely to suffer from these types of symptoms. More interesting is our finding that even with symptom severity held constant, there is still a gender bias towards diagnosing boys. Our analysis suggests that girls are less likely to be identified with ASD even when their symptoms are equally severe." The researchers suggested that the popular conception of autism as a 'male' disorder may contribute to this bias.

The study is available online: <http://bit.ly/ez2Zgc>

The In-betweeners

Christine Knight (Policy Research Fellow, Forum) and collaborator Claire Lightowler (Scottish Centre for Crime & Justice Research) have been examining an emerging species in the world of social sciences — the knowledge broker. Knowledge brokers can be people or organisations — like the Genomics Network and Forum — which help construct a bridge between the research and policy communities.

Invited to present their work at a symposium on Changing Academic & Professional Identities in Higher Education at the Society for Research into Higher Education Conference held in Newport, South Wales, in December 2010. The University of Edinburgh's Moray Endowment has funded a pilot study interviewing knowledge brokers in the College of Humanities and Social Science at the University.

See Knight & Lightowler, 'Reflections of "knowledge exchange professionals" in the social sciences': *Evidence & Policy* vol. 6 no. 4 (2010).

For a copy of the full paper or more information about the Moray Endowment study, email: christine.knight@ed.ac.uk

Cesagen's nutrigenomics project



As the Nutrigenomics project comes to completion, Dr Minakshi Bhardwaj's published outputs include an UNESCO Consultation Paper, as well as chapters in two forthcoming edited collections: *Genomic Variation and Genetic Disorders in Developing Countries*, edited by Dhavendra Kumar; and *Genomics and Bioethics: Interdisciplinary Perspectives, Technologies and Advancements*, edited by Soraj Hongladarom.

The project's key objective was to map the emerging social and policy issues, as well as the future trajectories, of nutrigenomics research and practice. As part of this, the project also engaged in an ethical analysis of the current situation and potential future trends. Expert interviews with scientists and policy experts upon the use of nutrigenomics in dietary advice and health management highlighted a growing concern over the gap between scientific developments and clinical applications.

To read more on this please visit: <http://bit.ly/e4Bq1Y>

Synthetic Aesthetics: designing the living world

'Synthetic Aesthetics' is an innovative project that has initiated new collaborations between synthetic biologists, engineers, designers, artists and social scientists to creatively work together on designing, understanding and building the living world.

Jane Calvert (Innogen) and Pablo Schyfter (Innogen affiliate, Stanford) are supporting and studying the project's exchanges as six synthetic biologists and engineers, paired with artists and designers, spend time working together in their partner's lab or design workspace.

In November 2010, Synthetic Aesthetics held workshops around the iGEM Jamboree (the International Genetic Engineered Machines competition at MIT) to critically explore what it means to design with nature and to delve into synthetic biology's relationship to design and art.

For further details and information on 2011 workshops visit: www.syntheticaesthetics.org



Get more gen online

If you're reading a hardcopy of this edition of the ESRC Genomics Network newsletter then you are missing out. Our online version offers all the same great content, in exactly the same layout, but now includes additional web links offering you access to even more information. Check out our online copy at: <http://bit.ly/e4FbLH>

Making headlines

In December, Dr Richard Twine (Cesagen) was commissioned to write for *The Scavenger*, an online magazine edited out of Australia described as an "online portal of features, commentary and news that you're unlikely to find in mainstream media. It's a mix of original articles, aggregated content (republished blog posts) and author extracts". His piece is entitled 'The industrialisation of animals: What happened to ethics?': <http://bit.ly/fjuUct>

Social media

Noticed our new social media web icons on the website? If you're not following our tweets, blogs and YouTube postings visit: www.genomicsnetwork.ac.uk to find out how to join in.

Rules of engagement

'What the Green Movement Got Wrong', aired on Channel 4 in 2010, and focused on the fundamental ideological shift by environmentalists towards new science and technology. Engaging in the show's online debate, Innogen's Joyce Tait blogged about 'the shadow' of the GM crop experience and the biased outcomes that can arise when public upstream engagement governs science innovation. She suggests 'rules for engagement' to better moderate the evidence brought to debates on scientific research. Read Joyce's blog: innogencentre.blogspot.com

Seminars coming online

Innogen regularly hosts thought-provoking seminars at both the University of Edinburgh and the Open University. For those who can't attend, recorded videos are now available to watch online at: www.youtube.com/user/genomicsnetwork

ESRC Genomics Network Conference 2012

Genomics in Society: Facts, Fictions and Cultures

Monday 23 and Tuesday 24 April 2012
British Library, Euston Road, London

To receive advance notice of registration information and programme details
Email: egenis@genomicsnetwork.ac.uk
www.genomicsnetwork.ac.uk/egenis



Selecting healthy embryos – who should have access?



Pre-implantation genetic diagnosis (PGD) is a technique that allows prospective parents to select embryos free from certain genetic conditions. PGD is strictly regulated in the UK: before PGD clinics are permitted to test for a condition, the regulatory authorities must first agree that the condition they want to test for is sufficiently serious. In addition, the NHS applies further medical and welfare criteria to decide who should have access to PGD.

Under what circumstances should parents be allowed to have embryo screening on the NHS? Who should be given access, and who should decide?

Gengage and the ESRC Genomics Forum invite you to join experts in a lively informed debate on the current use of PGD within NHS Scotland.

Part of the Edinburgh 2011 Science Festival, 'From Healthy Embryos to Designer Babies – how far is too far?' is a free public event held on Wednesday 20 April 2011 at the e-Science Centre, New College Street, Edinburgh.

For further information: <http://bit.ly/igLROc>

Cesagen Public Lectures



Cesagen's series of public lectures continues into 2011 with scheduled visits from Professor Allen Roses to Cardiff in March and Professor Sir Alec Jeffreys to Lancaster in October. Professor Roses will speak on the topic 'Predicting Alzheimer's disease: facing the challenges of genomics in medicine', while Sir Jeffreys will discuss DNA fingerprinting.

These lectures build on successful events in the latter end of 2010. Tim Lang (pictured), Professor of Food Policy at the University of Leeds, visited Lancaster in October to talk on 'Sustainable diets: Too complex, too nanny-state – or inevitable?' which stimulated debate on 21st century sustainable food systems. And in November Dr Sarah Darwin, great-great granddaughter of Charles Darwin, visited Cardiff to talk about her recent recreation of his famous HMS Beagle voyage. Before the lecture Sarah was interviewed on BBC Radio Wales' Good Evening show and the reception afterwards featured a display of artwork celebrating seafaring voyages, exhibited by Professor Steve Hughes (Co-Director of Egenis).

For more information on Cesagen's public lectures visit: <http://bit.ly/gvakZM>



Partying at the Conferences

At the autumn 2010 UK political party conferences the Network highlighted the significance of genomics and the relevance of our work to policy development across government. Attended by MPs, industry and charity representatives, each fringe event focused on a different topic.

At the Liberal Democrats event, 'Pills or Progress: What is needed to improve healthcare in Africa', Malcolm Bruce MP, Chair of the International Development Select Committee led discussions. The Conservative event, 'Why science needs social science,' was introduced by George Freeman MP, a strong advocate of UK science who has his own biomedical business.

'The Politics of Plants', with Simon Bright (Chair of Egenis Advisory Board) and Steven Hunt (Practical Action Consulting) helped an enthusiastic Green Party audience consider how plants can be a useful focal point for joined-up policymaking. At the Labour Party event, 'A secure society? Technological solutions to social challenges', Adam Hedgecoe and Paul McCarthy (both Cesagen) discussed emerging issues relating to border security and the regulation of dual use technologies, such as synthetic biology, which offers potential applications in both biological weapons and medicines.

Read our fringe blogs on Genotype: www.esrcgenomicsforum.blogspot.com

News Bites

→ Practical ethics

Dr Michael Arribas-Ayllon, and his colleagues Dr Katie Featherstone and Professor Paul Atkinson had their paper: 'The practical ethics of genetic responsibility: Nondisclosure and the autonomy of affect', published in *Social Theory and Health* in December 2010. This account of 'practical ethics' combines discursive and pre-discursive explanations to explore the role of inheritance, kinship and affect in the modulation of genetic responsibility.

→ GLEUBE Conference

In January 2011 Cesagen organised a conference as part of its involvement in the European Union funded GLEUBE (Globalising European Bioethics Education) project. Entitled 'The (Hi)story of Bioethics' the two main conference themes were *Developments in Bioethical Theory and Bioethics, Policy and Centres*. A keynote speech was given by Göran Hermerén, Chair of the European Group on Ethics in Science and New Technologies. For further details visit: www.gleube.eu

→ In debate at Manchester Science Festival

Dr Maureen O'Malley, Senior Research Fellow at Egenis, and Professor Steve Yearley, Director of the ESRC Genomics Forum, joined Professor Ron Weiss of Princeton University, a prominent scientist in the field of synthetic biology, to discuss 'Artificial life: Promises and pitfalls' at the Manchester Science Festival in October 2010. The recent creation of "artificial life" in a laboratory has highlighted the potential benefits – and the possible risks – of the emerging science of synthetic biology. The discussion explored the scientific background to the story, before opening up the debate to consider the broader social, economic and ethical implications of biological engineering.

HUGO – Whole Genome Sequencing Paper



The working group outside the Brocher Foundation, Geneva

This month (March 2011) Cesagen Director, Ruth Chadwick, will visit Dubai to chair a Working Summit on ‘Global Ethical and Legal Challenges in Genomics and Genetics’ at the Human Genome Meeting, and will present a position paper on whole genome sequencing.

The paper results from a working group at the Brocher Foundation, Geneva, in December 2010, convened and chaired by Ruth together with Edison Liu, President of the Human Genome Organisation (HUGO). The goal was to identify a number of specific ‘imagined futures’ for how sequencing technologies could be used, while having regard to the uncertainty that accompanies the societal uptake of any technology and the impossibility of predicting the future. Uncertainty applies also to future developments in mechanisms of oversight, ethics and regulation. The group identified three imagined futures to explore: clinical indications for whole genome sequencing (WGS); cancer genomics in diagnosis and theranostics; and microbial genomics and metagenomics. For more information on the Human Genome Meeting 2011 visit: hgm2011.org

Empirical ethics

A workshop marked the beginning of a new research collaboration between Egenis, the University of Oldenburg and the University of Utrecht. The participants discussed ethical aspects of empirical research, including the norms in collaboration and comparative research and the blind spots and value conflicts that need to be considered.

Marcus Duewell (Utrecht), presented on ethical questions with respect to the new research co-operation, Gesa Lindemann (Oldenburg) addressed the relationship between theoretical and empirical sociological research, Christine Hauskeller (Egenis) discussed ‘Problems in the empirical study of ethically contested subjects areas’, and Sigrid Graumann (Oldenburg) spoke about ‘Treatment decisions regarding premature infants’, which is the case study of collaboration. Discussants were Susan Kelly (Egenis) and Michael Hauskeller (Exeter).

Christine Hauskeller said, “I am very excited about this new collaboration, which offers great potential insight. We are looking at theoretical and conceptual questions about social theory and practice together with practical genetic applications in a setting of international comparison across the three countries involved in the study.”

Innogen and RAND support innovation

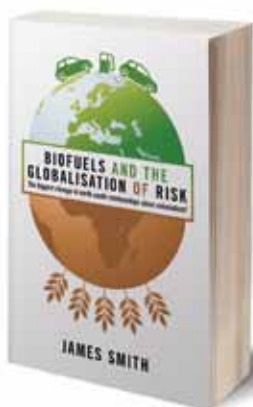
RAND Europe has been commissioned, on behalf of the Government Office for Science’s Food Research Partnership, to support innovation in the agriculture and food industry.

The project will develop a methodology to promote effective translation of research into services and products. It will be trialled on the UK wheat supply chain but the aim is that the methodology will be transferable to other value chains within the agri-food sector, as well as other life science based industries.

Joyce Tait (Innogen Scientific Advisor) has been invited to partner with RAND Europe to develop this work, together with the HGCA (the cereals and oilseeds division of the Agriculture and Horticulture Development Board) and Campden-BRI, all of whom bring expertise of the agri-food supply chain, knowledge transfer and translational research in these industries.

For further details visit: <http://bit.ly/eIIGj6>

New books authored and ideas explored



In 2010, staff published three new books – each distinct, but linked by the interdisciplinary, integrated approach to challenges facing the social sciences for which Innogen and the Network is renowned.

Nature After the Genome, published by Wiley-Blackwell and edited by Sarah Parry (Innogen) and John Dupré (Egenis), uses multidisciplinary case studies contributed by authors across the Network to unpick the

relationship between the evolving development of genomic technologies and our knowledge and understanding of 'nature'.

James Smith's *Biofuels and the Globalisation of Risk: The Biggest Change in North-South Relationships Since Colonialism?* published by Zed Books, examines the uncertainty of investing in biofuels and questions the potential impacts and implications of doing so.

Interdisciplinary Research Journeys: Practical Strategies for Capturing Creativity by Catherine Lyall, Ann Bruce, Joyce Tait and Laura Meagher and published by Bloomsbury Academic, is a practical guide for those looking to develop interdisciplinary research strategies at a personal, institutional and multi-institutional level.

For further details visit: www.genomicsnetwork.ac.uk/innogen/publications

Egenis postgraduate day

In the first event of its kind at Egenis PhD students spent a day presenting their work to supervisors and other academics.

During the event, organised by the students themselves, project presentations were followed by some rigorous questioning.



David Wyatt, who was presenting his project on the use of DNA in police practice, commented: "Not only is it extremely useful for us to practise presenting, but by bringing everyone in Egenis together and providing a forum in which we were able to hear about each other's research, it really enabled us to draw on the interdisciplinary perspectives available at Egenis to help develop our own work."

Full details of Egenis PhD projects at: <http://bit.ly/fYUDX9>

News Bites

→ Impeding innovation?

Joyce Tait and Joanna Chataway raise the questions: Has the uncritical adoption of the precautionary principle (PP) and 'upstream engagement' diminished the innovativeness and competitiveness of a European industry sector? Is it challenging future innovation in life sciences? In the *Appropriate Governance of the Life Sciences* policy brief, 'Pros and Cons of the PP', they critique the European experience with the regulation of GM Crops.

Visit: <http://bit.ly/h5YbAd>

→ Scottish Parliament discussions

In October 2010, Joyce Tait (Innogen), Alistair Elfick (University of Edinburgh) and Emma Frow (Genomics Forum) led a seminar exploring the vast potential of synthetic biology at the Scottish Parliament. In February 2011, David Castle (Innogen) again engaged MSPs, policymakers and researchers in a discussion on Scotland's potential role in enabling UK and global food security. The events were organised by Scotland's Futures Forum, who connect members of parliament with world-leading research undertaken in Scotland.

Visit: www.scotlandfutureforum.org

→ Bright ideas – we have a dozen!

In 2011 the Forum's Bright Ideas programme looks set to welcome over 12 visiting fellows. These flexible fellowships offer individuals a quiet environment in which to work and freedom from other constraints, whilst creating a stimulating and lively mix of scholars and artists with diverse interests centred on genomics. To find out who is visiting or for information on the scheme, including an application form visit:

<http://bit.ly/gSXxSx>



The Human Face of Data-Intensive Biology



There is a staggering amount of data produced within traditional laboratory research. Within molecular and systems biology, where high-throughput technologies such as genetic sequencing and micro-array experiments have changed the way in which data are produced, the activity of data gathering has become increasingly automated and technology-driven. This has resulted in the production of billions of data-points in need of a biological interpretation.

More important even than this quantitative change, there is a shift in how researchers expect to use data: not any longer as evidence for one given claim to be tested, but rather as potential ground for several discoveries in the future. As a consequence of these qualitative and quantitative shifts, massive efforts are being devoted to the dissemination of data online, in the hope that free and widespread access to large datasets will enable scientists to use them to understand biological phenomena, thus generating new paths towards discovery.

Data are now available to researchers on an unprecedented scale thanks to a large variety of computational tools, such as databases and modelling techniques, which make use of the internet to collect, store and distribute data.

This partnership between biology and computer science constitutes both a strength and a weakness. Several commentators have argued that the extraction of knowledge from large, cross-disciplinary datasets constitutes a new scientific method, often described as 'data-driven'. The underlying idea is that data already available online constitute formidable sources for the derivation of insight, and that these

“This partnership between biology and computer science constitutes both a strength and a weakness.”

data can be used to generate research programs without necessarily starting from a specific hypothesis to be tested and without necessarily possessing the same expertise as the original data producers.

In other words, data can be used to help biologists build meaningful research questions to be investigated in the future. For instance, the statistical analysis of microarray data can indicate areas of gene expression previously unnoticed, and generate a research programme exploring

Data-intensive science

Data-intensive research can be characterised as the attempt to extract biological knowledge from the huge amounts of data produced through experiment and technologies such as gene sequencing, and then disseminated through cyberinfrastructures such as databases.

Data-intensive research encompasses a wide variety of scientific methods, whose common feature is to rely on the accumulation and sharing of evidence on a large scale and across research contexts as a starting point for the research process. Also central to data-intensiveness is the idea of automated data analysis, defined as the extraction of biologically significant patterns from data through computational means, with as little human intervention as possible.

Computational tools for data mining are expected to aid the generation of new hypotheses and thus to help identify fruitful research directions, which can be explored further through in vivo experimentation. Yet both champions and critics of data-intensive research recognise that data analysis cannot be purely inductive and cannot be fully automated, because human skills, such as the ability to interpret data, construct models and formulate hypotheses, are involved.

A special issue on 'Data-driven research in the biological and biomedical sciences' is in preparation for publication in *Studies in History and Philosophy of Biological and Biomedical Sciences*.

this new phenomenon. At the same time, it has become clear that the sheer scale and diversity of data to be analysed requires the creation of sophisticated tools for data mining. 'Smart' software is assigned a prominent role in facilitating the extraction of patterns from data, either through statistical analysis or through search mechanisms in databases. But automated techniques for data analysis and hypothesis generation need to be informed by relevant expertise in the theory and practice of all the relevant domains within biology. Automation is an important aspect of post-sequencing biology, but is arguably not a solution to the problem of having to curate and interpret data. Expert human intervention is not only still necessary, but crucial to being able to make sense of the so-called data deluge.

There are two good reasons to believe that biological research cannot be fully automated. First, research within the field of bioinformatics has shown that data mining processes are only reliable if resources and expertise have been invested in selecting high-quality data for insertion in databases and in building databases that make use of efficient search engines. Indeed, data-intensive science cannot advance without substantial investment in a reliable cyberinfrastructure which can be easily updated by users. And the only way to ensure that a cyberinfrastructure such as a database is and remains effective is to rely on expert curators to build it and maintain it. Second, successful examples of data-intensive science illustrate the need for this type of practice to be embedded in a wider spectrum of scientific practices, ranging from theoretical analysis to experiments and field observations. Data-intensive research is only effective when used by experimental biologists as part of a wider spectrum of investigative practices.

The fact that good curation and constant user feedback are key to the development and use of databases means that supporting curators' work is vital to data-intensive science. In turn, this means that appropriate governance and funding structures are needed to guarantee the long-term sustainability of these resources. Government funding currently plays a crucial role in supporting online databases, but is likely to be unsustainable in the long term – witness the recently announced cuts in UK research funding. One of the most interesting research questions emerging in this area concerns precisely the forms of support that should power this emerging and important component of biological research. ■

Further information and publications list visit:

<http://bit.ly/grH11y>

<http://bit.ly/hXNeEt>

Contact: **Sabina Leonelli**,

S.Leonelli@exeter.ac.uk | Tel: 01392 725137

Conference

Making Sense of Large Datasets: Perspectives Across the Sciences

20-21 June 2011, Institute of Arab and Islamic Studies, University of Exeter.

Sponsored by Egenis and the Konrad Lorenz Institute for Evolution and Cognition Research.

A group of well-known scientists, philosophers of science and database curators will gather to discuss the advantages and problems of using large datasets. Debate these issues in a comparative perspective across several sciences, including biology, medicine, archaeology, and environmental and climate science.

This event is free and all are welcome, but spaces are limited. Please register with egenis@exeter.ac.uk or telephone **01392 725140**.



Director's Comments



All for one and one for all

Working together as the ESRC Genomics Network gives each of our four centres strengths and opportunities we would not enjoy working alone. Apart from the practicalities of sharing resources in order to create a newsletter such as this – too large an undertaking for a single centre – there are synergies across our work which, as our workstreams show, can often create a whole which is greater than the sum of its parts.

The conference which the EGN organised in concert with the OECD in December was a demonstration of the themes and interests which cut across our work and a clear expression of the overarching scrutiny the social sciences can bring to bear on the life sciences, and of how they can shape and direct the practical application of scientific research. The conference explored how knowledge in the life sciences is governed, shared, regulated and managed. On p.16 Steve Yearley reviews the conference's exploration of the key themes of knowledge networks and markets, and biodigital futures.

Within the Network, each centre makes its own distinctive contribution, and in *the gen* we plan to run a series of articles looking at the special contribution made to the EGN by each of the centres. The series begins in this issue, as Dave Stevens takes a look at the unique strengths of Innogen, the ESRC Centre for Social and Economic Research on Innovation in Genomics.

New questions for social scientists

Our era has been categorised as the information age. As this newsletter makes clear, the governance, regulation and management of the exponentially growing quantities of biological data give rise to a range of intriguing new questions for social scientists. The tsunami of data produced, for example, by whole genome sequencing crystallises questions about how to deal with huge quantities of information, how we

pick out what is useful, how we see patterns, how we work out how to apply our new knowledge. How much information can we gather before it stops becoming useful because the sheer volume is overwhelming?

Sabina Leonelli's article on p.10 explores some of the questions around data-gathering, looking at the shift in how researchers in the biosciences use data, the curation and use of databases, and the sharing of information. One of the issues she raises is the need for appropriate governance and funding structures to guarantee the long-term sustainability of these resources.

Neil Stephens' article (p.21) is a cautionary tale in this respect, being a case study of one resource, a tissue bank set up to aid cancer research but forced to close with its remit unfulfilled. "The case ... raises questions about how we plan and deliver ... resources," writes Neil.

On a quite different note 'network people' on p.27 highlights the retirement of a founding Director of Egenis. Barry Barnes will be greatly missed by everyone who worked with him in the EGN and he is a reminder of another of the Network's vital roles, the nurturing of younger scholars. Part of Barry's legacy will be the intellectual enrichment he has provided for scholars young and old, but perhaps especially those whose careers he helped to launch. All the EGN's centres provide a remarkably fruitful environment for budding scholars, offering wonderful opportunities to meet and mix with academics of international standing. It's a different kind of knowledge network, but a no less important one.



Pushing the Boundaries at Innogen

Dave Stevens, freelance science writer, takes a look at the outside interests which are leading to a greater diversification at Innogen.

After almost ten years, the Network and its constituent centres have become established features in – what has ultimately become – a varied genomics landscape. Now this work is also being noticed beyond the extensive borders of the life sciences, with staff being actively sought out to apply their expertise in ‘pastures new’.

This demand is clearly seen at Innogen, whose large membership and collaborations with national and international institutions, including those from the social sciences, natural sciences, law and medicine, are one demonstration of its interdisciplinarity both within and beyond the life sciences.

“Innogen is now the innovation centre in the life sciences. But it has also developed a range of approaches that are no longer seen as just being useful in the life sciences, and are already being used more broadly in the social sciences,” says Innogen Director, Professor Dave Wield.

As Wield explains, one of Innogen’s strengths – and what puts it in good stead for the future – is its strong academic vision, allied to a clear purpose. It might have begun as a centre to research the social sciences of genomics, but its research and engagement now goes well beyond the social science of science, technology and medicine.

“It’s quite clear that beyond 2012 Innogen will maintain its emphasis on innovation and hopefully the tools, techniques and approaches we develop will continue to be more useful generally in the social sciences and beyond.

“For instance, we are strongly international, bringing together expertise in the health, food and energy sectors at a time when there is growing convergence of information and environmental technologies with the life sciences.”

A QUEST for knowledge

That such expertise is already having an impact outside the world of genomics is evident. Drawing on their collective experience in interdisciplinary research across the life sciences and beyond, Innogen researchers have sought to

share their skills in the conduct, management and evaluation of interdisciplinary research with the wider research community through a series of Interdisciplinary Masterclasses. These training events were set up in order to develop a cadre of students, researchers and research managers who are better able to tackle the challenges of interdisciplinary research across a range of domains.

“Innogen...has also developed a range of approaches that are no longer seen as just being useful in the life sciences.”

“The Masterclass model has worked extremely well as a way of conveying codified knowledge but also, crucially, tacit knowledge of how interdisciplinary research can be conducted,” says Deputy Director, Dr Catherine Lyall.

“By recognising that skills gaps persist at the early – and mid-stage in interdisciplinary careers, we have been able to develop a systematic approach through our short courses to a phenomenon that in the past has often been rather bespoke and craft-based.”

These Masterclasses have acted as an important catalyst for a wide range of other capacity-building activities which have consolidated Innogen’s position as an international leader in the field of interdisciplinary research spanning the social and natural sciences.

This expertise has already been acknowledged by NERC, who commissioned Innogen researchers, led by Lyall, to conduct a yearlong study centred on four interdisciplinary programmes:



QUEST - Quantifying and Understanding the Earth System, the Rural Economy and Land Use Programme, the Climate Change Research Programme at the Tyndall Centre and the UK Energy Research Centre to tease out the transferable lessons that would be of relevance to other interdisciplinary initiatives.

This same team has also produced the widely applicable, practical guidebook, *Interdisciplinary Research Journeys*, scheduled for publication in March by Bloomsbury Academic.

Sustainability

And on a similar environmental theme, Innogen's Dr Sarah Parry is part of the newly funded, UK-wide Sustainable Practices Group, which is focusing on understanding social, and specifically consumer, behaviour and how it might be encouraged to become more sustainable.

This, on the face of it, might seem a leap from Parry's previous work looking at public engagement with stem cell research. But she says it illustrates perfectly just how one of Innogen's approaches is finding new, wider applications.

"The main expertise I carry forward is analytical, trying to answer questions about the nature and role of different types of knowledge and expertise, especially as these relate to policy, and questions of power and influence therein."

The Group, funded by the ESRC, DEFRA and the Scottish Government, will deliver an analysis of three environmentally-sensitive practices: eating, water-use and sheltering. Each research project will answer questions regarding how habits operate and identify the drivers of change. The programme is designed to enhance the social scientific understanding of how habits in areas of everyday consumption form, reproduce and may be changed.

The stem cell project Parry previously worked on had two aims: first, to explore the views of a wide range of publics and experts in Scotland and, second, to develop engagement methods for establishing a dialogue between the different

groups. The sustainable consumption research will involve establishing new ways of thinking about behaviour in political, policy and public debate and will lend understanding to current policy-related processes concerning sustainable consumption. "It's the more fundamental conceptual approaches that underpin the two projects that make the links between them," says Parry. "It's the analysis of public engagement and its role in policy and politics that is being taken forward, not public engagement itself. The interesting thing for me is that the [Sustainable] Practices work doesn't so much as overlap with the stem cell work, but it's more that it starts where the public engagement work ended."

The future is bright

It's clear then that many of the techniques and approaches developed at Innogen over the last decades have attracted considerable attention outside of their original spheres of use, and have drawn some staff into new and unexpected areas of research; areas probably never envisioned as within its remit during the Network's conception. Such greater application puts Innogen, the Network and UK Social Science in a stronger and more visible position heading into the next decade.

Wield sums it up best: "Our vision is to find ways of doing new science, technology and medicine that value and embed the contribution of the social sciences. Innogen and post-Innogen futures depend on our continued enthusiasm and creativity to build a new social science."

And there's more...

Read how Innogen's research has developed a toolkit to support regional R&D policy formulation, and how it is increasing understanding of the relationships between finance, economics and innovation. ■

For the full text of this article visit:

www.genomicsnetwork.ac.uk/innogen/research/



BIODIGITAL FUTURES →

The Social Science of the Genome

**Organising a dialogue with the OECD's
Working Party on Biotechnology.**





Delegates at the Genomics Network/ OECD conference

The ESRC Genomics Network has been running unified network conferences every year since 2007 but the meeting for 2010 was rather different. It was targeted at a policy audience and was co-hosted at the OECD headquarters in a stately quarter of Paris. The attendees were composed in almost equal parts of academics and people from the worlds of policy.

Virtually everyone acknowledges that the contemporary life sciences have significant social and political dimensions. It is widely held that life-science innovations could allow us to revolutionise the relationship between health insurers and their customers, transform agriculture and the production of biofuels, offer new kinds of understandings of diseases and ill-health and allow humans to design entirely novel forms of living cells to do new jobs for us – whether to make energy or clean up toxic chemical spills. But this strong social component doesn't necessarily mean that social scientists have been invited to play a big role in investigating, laying out and evaluating these societal aspects.

On the contrary – in many cases it has been the scientists and technologists, innovators and entrepreneurs who have set out their own vision of the social implications alongside their new technical prescriptions and devices. Companies that offer online genetic tests, for instance, tend to conjure up an idea of informed, autonomous citizens using their personal information to promote healthy lifestyles and well being. Such visions are an integral part of the marketing of new technologies but they are seldom based on solid social research and many commentators and activists feel these visions are fundamentally misleading.

To provide focus, the two day meeting at the OECD was organised around two principal themes: 'Knowledge Networks and Markets' and 'Biodigital Futures'.

“

The Genomics Network was keen to take the opportunity of the OECD meeting to display the richness and practical relevance of systematic social-scientific work on these life-science questions.

”



Gerardo Jiménez-Sánchez, Chair, OECD Working Party on Biotechnology with Steve Yearley



Jennifer Leib, HealthFutures LLC

Knowledge Networks and Markets

The first of these was fundamentally concerned with the question: is knowledge in the life sciences – and the products and services to which that knowledge gives rise – distinctive? For example, conventional technological innovation leads to products that may be copied, but only the life sciences generate products that can breed and evolve. How then can life-sciences products be brought to market in a way that rewards innovation, and how can new products and ideas be shared around networks that include researchers, community organisations and firms?

Regulation by government and international bodies is critically important in many areas of the life sciences, from stem cells to the treatment of genetic information. But social scientific work shows that these regulations commonly have unintended and unanticipated effects. For example, attempts have been made in the Netherlands (and elsewhere) to limit the use that insurance companies and employers can make of genetic/genomic information about citizens and employees. The intended societal benefit of such moves seem clear – health insurance seems fundamentally designed to share the rough and the smooth, and one wouldn't want insurance companies only to cover cheap-to-insure citizens. But these developments have led to the distinction between genetic ill-health and other forms of unwellness becoming more critical. Companies cannot discriminate on genetic grounds but they may still choose their customers on other health-related

grounds. These disputes have led the parties to query and quarrel over exactly which forms of misfortune are genetic and which are not. And that turns out to be a hard problem to resolve in a definitive way.

Another key focus for the work on knowledge networks and markets has been on developing economies, where the potential benefits of life-science innovations are very high but where there are major impediments to the realisation of these benefits. For example, one could imagine new technical approaches to diseases that are widespread in poorer countries, but where would the funding for such research come from? Social scientists have been studying different arrangements such as public-private partnerships (PPPs) intended to overcome these difficulties. Economic and sociological studies have indicated that – organised well – these PPPs can foster long-term collaborative networks that promote novel applied research and help to move the results down the 'pipeline' to production and use.

Finally, this strand of the meeting focused social-scientific expertise on exploring the way in which life-sciences futures are imagined, valued and mobilised in the present. For example, how realistic are ideas about green innovation and new sources of therapeutic molecules and how feasible are new models of growth based around the bioeconomy? What is the evidence that they are more than 'greenwash'? Social scientists pointed out that claims about green production are often correct in narrow technical terms but are less persuasive when all the knock-on effects are properly assessed.

Biodigital Futures

The second theme had a rather more technical title: ‘Biodigital Futures – Informatisation and Convergence in the Life Sciences’. In more straightforward terms, this theme addressed the prospect that the life sciences and ICTs (information and communication technologies) can converge in so-called ‘biodigital’ approaches. This convergence can occur both in terms of research and in relation to novel products and services.

Many futurologists and science-fiction authors think hard about this convergence. One key focus is on the so-called ‘informatisation’ of the life sciences – this is the idea that we can think of biological information as written in a kind of computing language. Here, our genomes are a form of software (sometimes called ‘wetware’) and technologists could think about using DNA to ‘do computing’. Even more topical are attempts to move into the design of living entities (usually bacteria or yeasts) to do simple jobs for us. Developments in this field frequently aim to build organisms using standardised biological components – building biological ‘circuits’ inspired by models from microelectronics – See p.20.

Though this vision of convergence is profound in scientific and philosophical terms, the life sciences and ICTs do not come together only in these circuits and codes. Much more important in the immediate term are connections between the life sciences, the growth of ICTs and the availability of the World Wide Web. Increasingly, genetic testing services are available over the web; you send off your cheek swab (or someone else’s) in the post and you get your data via the Internet. Global, web-based access to testing and diagnostic services can easily generate regulatory tensions. Tests that, say, a European government regards as of low quality or as undesirable may be provided to their citizens by companies based elsewhere in the world.

Finally, social scientists have observed the way that the practices of the biological sciences are themselves being impacted by the growth of web-based genomic data. With the rapid growth of statistically searchable biological databases and the rise of bioinformatics as a scientific specialism, more and more biology is being done by interrogating databases rather than by conventional hypothesis-testing. This is a whole new aspect of convergence between ICTs and the life sciences and social analysts of science have highlighted its impact on the shaping of the research agenda in the biological sciences.

Promise of a better future?

In all, this innovative conference highlighted a number of ways in which detailed social scientific work can provide critical insights and intelligence for the policy community.

The policy audience was left both with concrete examples of what the social sciences can contribute to the contemporary understanding of genomics and with a sense of the continuing importance of social scientific work in this fast-changing area. As Iain Gillespie Head of the OECD’s Science and Technology Policy Division noted, “The life sciences offer huge potential for green growth and for better lives. As all governments are looking for sustained and sustainable recovery, getting policy right on critical drivers for growth has never been more important. This is why the OECD is taking a systematic look at what the social sciences can bring to international policy-making in science and technology.”

Delivering Global Promise Through the Life Sciences

For full details of the ESRC Genomics Network 4th International Conference – Delivering Global Promise Through the Life Sciences visit the dedicated conference website offering reports, speaker presentations, photos, and blog posts.

www.genomicsnetwork.ac.uk/forum/conference2010/

Our next ESRC Genomics Network Conference

Genomics in Society: Facts, Fictions and Cultures – will be held in London on 23-24 April 2012
See advert on p.5



Rob Carlson, Biodesic answers a synthetic biology question during the conference session chaired by Emma Frow

Looking ahead: Setting standards for biological engineering

Dr Emma Frow, Research Fellow, ESRC Genomics Forum talks about how Network researchers are developing some of the synthetic biology projects and activities discussed at the EGN-OECD conference.

One cross-cutting area we've been focusing on for a few years now is synthetic biology, an emerging discipline that strives to apply engineering principles to designing biological systems. Using toolkits of biological components, synthetic biologists work to design and build genetic circuits that carry out specialised functions. Examples of applications that are now getting close to market are microbes that have been engineered to produce biofuels or to make drugs (such as the anti-malarial drug artemisinin).

In policy circles, the promise of synthetic biology is sometimes described in terms of heralding a new 'industrial revolution' in biological engineering, and of helping to foster the development of a more sustainable, 'bio-based' economy. But to achieve these aims there is still much scientific groundwork to be done. Synthetic biologists are currently devoting a lot of effort to questions of how to standardize and characterise biological systems — important for producing reliable 'biofactories'. With Genomics Network colleagues, I'm fortunate in being able to study and work alongside

synthetic biologists as they develop foundational toolkits and technologies for this emerging field. This is an area where social science perspectives can contribute to scientific debates — standardisation is an important topic for social scientists. We're interested in questions like what the best time is for setting standards (to avoid getting 'locked-in' to a suboptimal system), and the kinds of social and political choices that can go into making standards. Decisions being made in the laboratory now will have consequences for the shape of future synthetic biology markets, and it's important to bring a variety of perspectives to the table during these early efforts. This is just one example of how the Genomics Network plans to continue working at the interface of science, society, and policy in innovative ways. ■

For more information, check out the UK Synthetic Biology Standards Network: www.synbiostandards.ac.uk

Organisation for Economic Cooperation and Development

OECD brings together the governments of countries committed to democracy and the market economy. For more than 40 years, OECD has been one of the world's largest and most reliable sources of comparable statistics and economic and social data, providing a setting where governments compare policy experiences, seek answers to common problems, identify good practice and coordinate domestic and international policies. Visit: www.oecd.org



**onCore UK:
The £4m Cancer
Tissue Bank that
Closed**



For the last two years Neil Stephens has been conducting ethnographic research on a cancer tissue bank: onCore UK. When Neil started work, onCore UK was a functioning biobank, but today it no longer exists. This article tells the story of onCore UK and asks how its closure leads us to reflect upon the promise of tissue banking.

The last decade has seen an increase in the formalisation of tissue collections into tissue banks: centralised holdings of ethically-sourced human tissue for research purposes. Their growing number is in-part a response to the Alder Hey organ retention scandal and 1999 public inquiry that led to the storage of human tissue coming under the scrutiny of the Human Tissue Authority.

Established in 2005, onCore UK received £4m funding from the Department of Health (50%), Cancer Research UK (25%) and the Medical Research Council – MRC (25%). It was a response to a National Cancer Research Institute portfolio evaluation that identified access to human tissue as a recurrent problem for researchers. Initially conceived of as the National Cancer Tissue Resource, onCore UK was devised to increase the flows of ethically-sourced, data-linked and quality-assured human tissue to researchers, against a backdrop of unevenly distributed localised tissue collections. It would be community orientated, networking widely with professionals and patients: developing a ‘donor forum’ to inform and empower individuals with cancer. It sought to share best practice within the cancer biobanking community. As a charitable company limited by guarantee it was an innovative institutional form in biobanking, working as a not-for-profit charity intended to engender the trust lost during the preceding organ retention scandal. As such it formed a response to the Human Tissue Act demonstrating accountability and governance in cancer tissue storage, operating with a Board of Trustees and an independent Ethics and Standards Advisory Panel to guide its activities. Most of all, the bank promised a contribution to improved cancer care.

In 2006, onCore UK developed strategic allegiances with a number of NHS trusts to collect tissue donations, forming ‘Biosample Donation Networks’. Each agreed targets and procedures for patient identification, enrolment and biosample collection. They collected blood and tumour samples from any willing cancer patient, providing it did not impact on their clinical care. Enrolment occurred through several mechanisms, including the distribution of a set of posters (see fig 1 on p.23). The informed consent process used ethically reviewed consent documents and patient details were collated on in-house software.

Through the Confederation of Cancer Biobanks, onCore UK worked to develop best practice in the sector, organising

workshops and conferences on biobanking governance, informed consent and quality issues in tissue storage. As part of this, it conducted a survey that found widespread confusion and anxiety among NHS pathologists about the existing regulatory framework for supplying tissue for research. In response they arranged further workshops addressing this topic.

“ They collected blood, tumour, and unaffected tissue samples, from any willing cancer patient providing it did not impact on their clinical care. ”

However, May 2009 saw onCore UK receive directions from their Board of Trustees to cease biobanking activity and instead adopt an advocacy and advisory role for the UK cancer biobanking community. The board were disappointed that the Biosample Donation Networks were not collecting tissue at the rate dictated by their targets. They were also aware of other Banks in the cancer sector that experienced a complex relationship with onCore UK as disseminator of best practice, collaborator and competitor. However, the board recognised onCore UK’s work tackling issues around standardisation, ethics, and the profile of cancer biobanking. By ceasing the costly practice of biobanking the original grant for onCore UK could maintain the organisation in a new advocacy role for around two more years.

But the loss of biobanking activity also meant job losses for the biobanking and computing staff. The remaining staff had to devise mechanisms for distributing the existing tissue collection. Much of this was returned to the originating hospitals with limited quantities distributed to research applicants. The remainder was destroyed.

In its new role a streamlined onCore UK of four staff members continued to organise workshops and events on consent issues and Quality Assurance. The posters they developed to promote their own collection activities were offered to other banks, with one being trialled in Scotland. After taking on the secretariat of the Confederation of Cancer Biobanks, attention turned to the potential for creating an accreditation scheme highlighting best practice in the sector.



Fig 1: onCore UK promotional posters

Then, in October 2010, the day before the coalition government’s Comprehensive Spending Review, the Board of Trustees made another announcement stating that, while a sub-section of the advisory activities of onCore UK should continue, they should be conducted by other organisations under the National Cancer Research Institute (NCRI) umbrella.

“The case of onCore UK raises questions about how we plan and deliver community resources.”

This transition was completed in February 2011 when the remaining two members of staff switched organisation, and onCore UK ceased to exist as a charity, remaining only as a website and branding for NCRI activities.

The case of onCore UK raises questions about how we plan and deliver public and third sector resources. The organisation was launched with broad support and grand promises about addressing patient and researcher needs while spreading best practice in the disparate cancer tissue collection field. Yet within five years the organisation and tissue collection were disbanded with only a limited amount of its work continued in a new institutional form.

onCore UK is not the only non-profit biobank to disband, the UK Human Tissue Bank closed in late 2009. Meanwhile other banks open, including the Breast Cancer Campaign Tissue Bank, established after a report by the charity identified access to human tissue as a recurrent problem for researchers. Indeed, this bank took the largest proportion of the onCore UK holdings after it disbanded its collection. In 2009 the MRC established the UK Brain Banks Network, intended to co-ordinate UK-wide activity and develop gold-standards in technical and ethical practice, although importantly, and unlike onCore UK, it will not establish a competitor tissue collection to those in the network.

All these institutions are launched with lofty goals and far-reaching promises that reach much further than the underlying funding strategy supporting them. The case of onCore UK invites us to remember that while tissue banks promise to lend stability to the supply of ethically-sourced human tissue, in reality as institutions they can struggle for stability themselves. ■

For further details, or to contact Neil Stephens, visit: <http://bit.ly/f863Aw>

For onCore UK’s website visit: www.oncoreuk.org

The ESRC Genomics Network hosts and sponsors a wide variety of events aimed at social scientists, scientists, policy makers and the public. Events are held across our research centres and at the Genomics Forum. For the latest information visit the event section of our websites www.genomicsnetwork.ac.uk

March

Cesagen Public event: 5 March 2011

Discover! Club: 'Bimbos or Boffins?'

Venue: Cardiff University Council Chamber / Julian Hodge Study Centre, Cardiff University

Time: 9.30 – 12.30pm

Contact: haranJ@cardiff.ac.uk | 029 2087 5386

Egenis Seminar: 14 March 2011

DNA as a memory site: perspectives from 'Jewish genetics'

Speaker: Dr Yulia Egorova, Durham University

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

Innogen Seminar: 14 March 2011

The Challenges of Interdisciplinarity

Speakers: Professor Wyn Grant, University of Warwick & Dr Andrew Barry, University of Oxford

Venue: Chrystal Macmillan Building, University of Edinburgh

Time: 2.30 – 5.00pm

This seminar will also be recorded and available online.

Contact: Angela.McEwan@ed.ac.uk | 0131 650 9113

ESRC Genomics Network Workshop: 17-18 March 2011

'Making it Big?' Tracing collaboration, complexity and control in the biosciences

Speakers: Jane Calvert, Gail Davies, Rebecca Ellis, Emma Frow, Stephen Hilgartner, Sabina Leonelli, Kaushik Sunder Rajan, Niki Vermeulen

Venue: Reed Hall, University of Exeter

Time: 12.30 – 5.00pm

Organised by: Emma Frow (Forum), Gail Davies (UCL) & Sabina Leonelli (Egenis)

Further details: <http://bit.ly/i93y09>

Egenis Seminar: 21 March 2011

Doing knowledge: Science, practice, and policy making

Speaker: Dr Barbara Prainsack, Centre for Biomedicine and Society, King's College London

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

Egenis Seminar: 28 March 2011

Human ES and iPS cell-derived cardiomyocytes

Speaker: Dr Nadire Ali, National Heart and Lung Institute, Imperial College London

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

Cesagen Public lecture: 31 March 2011

Predicting Alzheimer's disease: facing the challenges of genomics in medicine

Speaker: Professor Allen Roses (Duke University)

Venue: Main Council Chamber, Cardiff University

Time: 5.30pm

Contact: hedgecoeam@cardiff.ac.uk | 029 2097 0024

April

Innogen Seminar: 11 April 2011

Socio-ethical aspects of the IVF-stem cell interface

Speaker: Professor Erica Haimes, PEALS, University of Newcastle

Venue: Seminar Room 1.06, Old Surgeons' Hall, High School Yards, University of Edinburgh

Time: 3.30 – 5.00pm

Contact: Angela.McEwan@ed.ac.uk | 0131 650 9113

Forum Free Public event: 13 April 2011

Genomics Poetry Competition: Reading Party

Venue: Scottish Poetry Library, 5 Crichton's Close, Canongate, Edinburgh

Time: 6.30 – 8.30pm

Part of the Edinburgh Science Festival – join winners for readings and a toast to poetry and science.

Organised by: ESRC Genomics Forum and the Scottish Poetry Library

Further details: www.spl.org.uk/events

Free Public event: 20 April 2012

From Healthy Embryos to Designer Babies – how far is too far?

Venue: e-Science Centre, New College Street, Edinburgh.

Time: 2.00 – 5.00pm

Part of the Edinburgh Science Festival

Further details: <http://bit.ly/igLROc>

May

Egenis Seminar: 9 May 2011

Forensic DNA Databasing Policy & Practice: Imagining and Assessing Utility

Speakers: Professor Robin Williams, Durham University

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

Egenis Seminar: 16 May 2011

Genetic screening for familial hypercholesterolemia: what does it mean?

Speaker: Dr Nina Hallowell, Newcastle University

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

Cesagen Seminar: 17 May 2011

A measure of control for the corporate experiment?

Speaker: Dr Catherine Will, School of Law, Politics and Sociology, University of Sussex

Venue: Railway Room, Cardiff University

Broadcast via video link to Lancaster University

Time: 1.00pm

Contact: bartletta@cardiff.ac.uk | 029 2087 0488

Egenis Seminar: 27 May 2011

Medicine, innovation and the humanities

Speaker: Professor Maurice Biriotti, SHM Productions

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

June

Egenis Seminar 13 June 2011

Emerging Forensic DNA Technologies: Risks, Realities and Representations

Speaker: Dr Chris Lawless, ISSTI, University of Edinburgh

Venue: Byrne House, University of Exeter

Time: 3.00 – 4.30pm

Contact: c.h.packman@exeter.ac.uk | 01392 725126

Cesagen Seminar: 14 June 2011

Genomics and race discourse in Latin America

Speaker: Peter Wade, Professor of Social Anthropology, Manchester University

Venue: Lancaster University

Broadcast via video link to Cardiff University.

Time: 1.00pm

Contact: o.forero@lancaster.ac.uk | 01524 5108372

Egenis Conference: 20-21 June 2011

Making sense of large datasets: Perspectives across the sciences

Speakers include: Alberto Cambrosio (McGill University), Paul Schofield (University of Cambridge), Rachel Ankeny (University of Adelaide), and Werner Callebaut (KLI)

Venue: Institute of Arab and Islamic Studies, University of Exeter. Sponsored by the Konrad Lorenz Institute for Theoretical Biology (KLI) and Egenis

Time: 1.00pm

Contact: s.leonelli@exeter.ac.uk | 01392 725137

Conference: Wednesday 22 June 2011

Gengage Annual Conference

Venue: The Royal Society of Edinburgh, Edinburgh

Organised by: Gengage – the Scottish Healthcare Genetics Public engagement Network

Further details: www.gengage.org.uk/events.php

August

Forum Public events: 13-29 August 2011

Edinburgh International Book Festival

Venue: Charlotte Square, Edinburgh

Contact: alison.caldecott@ed.ac.uk | 0131 651 4746



A new Chair for David Castle in Edinburgh

Innogen welcomed the arrival of **Professor David Castle** to the University of Edinburgh in September 2010. Appointed Chair of Innovation in the Life Sciences, he will support the continued development of Innogen's international networks and collaborations, maintaining the centre at the forefront of the study of life science innovation.

Professor Castle also leads on the International Barcode of Life Project (iBOL) for GE3LS (genomics and its related ethical, economic, environmental, legal and social aspects), and is co-Principal Investigator for the research network 'VALGEN' (Value Generation Through Genomics and GE3LS), which supports research on social aspects of science and technology innovation. Formerly the Canada Research Chair in Science and Society, his interest and expertise includes life science innovation and social aspects of biotechnology; intellectual property and knowledge management, regulation and governance and democratic engagement; food security, agricultural and industrial biotechnology, genetic barcoding, and human genomics. <http://bit.ly/i6CDlw>



Congratulations to Cesagen's recent Doctoral successes

Dr Jacki Hughes' PhD study "After Genetics – Huntington's disease, local data, global neuroscience" considers the effects of a research clinic with a dual role which includes disease management, and the 'shift' of Huntington's disease into neurology from genetics. Three analytic themes reveal: 'blurring' between the boundaries of research and care, performance and practice enacted in the clinic, and the creation and maintenance of hope and its utilisation in research aims. <http://bit.ly/dWO5qt>



Mr President

Egenis Director **Professor John Dupré** has been elected president of the British Society for the Philosophy of Science for 2011-13. The BSPS was founded more than 50 years ago to study the logic, the methods, and the philosophy of science, as well as those of the various special sciences, including the social sciences. Prof Dupré has also been elected a Fellow of the American Association for the Advancement of Science, Division of the History and Philosophy of Science. As the AAAS itself says: "Election as a Fellow of AAAS is an honour bestowed upon members by their peers. Fellows are recognized for meritorious efforts to advance science or its applications." <http://bit.ly/hWm1Z4>



Phil Strong Memorial Prize 2010

Innogen PhD student, **Rampaul Chamba**, received the 2010 British Sociological Association (BSA) Medical Sociology Phil Strong Memorial Prize for work on his PhD, 'Bio-medical and Social Explanations for Schizophrenia among Black African-Caribbean People'.

British born African-Caribbean's are over-represented within psychiatric in-patient facilities, and more likely to be diagnosed with schizophrenia, than other ethnic groups. Rampaul's research aims to answer the question of how and why bio-medical mental health researchers and non-biomedical mental health professionals support and contest the truism that Black African-Caribbeans are more susceptible to developing schizophrenia than other racial/ethnic groups in England. <http://bit.ly/fXxVwg>



Further Doctoral success at Cesagen

In her study 'Health & the Human Genome Project: an analysis of the health impacts of genetic technologies using a broad model of health', **Dr Jane Miller** assessed the impact of some of the reported uses of technologies arising from the Human Genome Project. These were analysed through the use of the moral theory of Alan Gewirth and in light of the endorsed model of health. <http://bit.ly/fx3pqz>



Founding Director retires

Last autumn saw the retirement of an Egenis founding Director, **Professor Barry Barnes**. Barry had been Director of the Science Studies Unit in the Faculty of Science and a Professor of Sociology at Edinburgh University. In 1992 he moved to the established chair in the Department of Sociology at the University of Exeter before becoming a Co-Director of Egenis.

Barry is renowned for his pioneering work on the sociological study of knowledge generation and evaluation in science, and on the basis of the credibility of scientific expertise. He is the author of seven books, five edited or jointly authored books, and more than 50 major papers. Egenis Director John Dupré said: “Barry is a world-leading figure in the sociology of science. He is also a wonderful colleague; his breadth of knowledge and scholarship, his wise advice, and his wit, will be greatly missed.”

“Barry is an inspirational enthusiast with a gift for spotting those interesting angles and arguments which elude most of us. It was a great experience to share an office with him. We wish him well,” added Co-Director Steve Hughes.



Tribute to Jim Jackson (1947-2011)

We are sad to report the unexpected death of our friend and colleague **Jim Jackson, OBE** in January 2011. Following a successful career as Chief Executive of Alzheimer Scotland (1994-98), Jim completed an MSc (Translational Medicine) with distinction at the University of Edinburgh, where he then commenced a PhD with Innogen in 2010. He pursued his proposed PhD thesis – exploring how translational medicine differs from conventional medicine and how it might be evaluated – with great enthusiasm. He will be greatly missed.
<http://bit.ly/fthCsD>

Staff moves

Cesagen

It's au revoir and not goodbye to **Dr Michael Arribas-Ayllon** who has been appointed Lecturer in Cognitive and Biological Psychology, Cardiff School of Social Sciences, but looks forward to continuing his collaboration with Cesagen. Our best wishes also go to **Keith Calvert**, Centre Secretary who has left to take up an appointment as Residences Officer at Lancaster University and will be replaced in post by **Tish Brown**.

We are delighted to welcome back **Amanda Eveleigh** as Centre Administrator. And wish **Mel Evans** and **Flo Ticehurst** all the best during their maternity leave. Covering these roles will be **Heather Strange** (Centre Manager) and **Simon Read** (Communications Officer). Both are based at Cesagen Cardiff.

Egenis

Congratulations to **Dr Sabina Leonelli**, who has returned to work at Egenis following the birth of her first child, Leonardo, last September.

Congratulations of a different kind to **Dan Nicholson**, who successfully completed his PhD in October. Dr Nicholson has now taken up a two-year post-doctoral research fellowship at the Konrad Lorenz Institute in Austria.

In January Egenis bid a fond farewell to Senior Research Fellow **Dr Maureen O'Malley**, who has taken up a new post at the University of Sydney.

We also said goodbye to **Dr Matt Hodges**, who has gone to the University of Kent, and to **Dr Mathias Grote**, who has now completed the Exeter 'leg' of his two-year research collaboration between Egenis and the Max-Planck Institute in Berlin.

Next month (April) Egenis welcomes as Associate Research Fellows **Jean Harrington** and **Daniele Carrieri**. Jean and Daniele have both been PhD students at Egenis, and will now be supporting Senior Research Fellows with their projects.

Forum

Jane Wilkin has recently been appointed as network co-ordinator for Gengage – The Scottish Healthcare Genetics Public Engagement Network managed by the ESRC Genomics Forum. Jane has a background in public engagement and takes over the role from **Dr Kathryn Hunter** who left in September to take up a Lectureship at Northumbria University.



Winning Poem Offers a New Twist on ‘improving the human’

Crafted in the form of a double helix and addressing the issue of cloning, ‘Forward Deck’ by published Edinburgh writer, Sophie Cooke, was awarded first prize in the ESRC Genomics Forum Poetry Competition. Pippa Goldschmidt, Genomics Forum Writer in Residence was the inspiration behind this competition and tells us what convinced her to launch such an unusual challenge to poets.

The idea for running a competition for poetry inspired by genomics came to me after the great response we received to the short story competition we ran at the Forum last year. I was intrigued to find out how poets would respond to the challenge of writing about ‘Improving the Human’, because there have been quite a few anthologies of poetry inspired by science; such as ‘Dark Matter’ (poetry meets outer space), and ‘A Quark for Mister Mark; 101 poems about science.’

Poetry has a reputation for being more oblique and ‘difficult’ to read than prose, and you might assume it is the antithesis of science writing which simply aims to clarify and explain. So how can poetry get to the heart of a science? By providing much needed commentary, by using language and metaphor to crack open the subject and get to its heart. And what poetry and science share is a need for precision. Poetry only works when every word of a poem is the right word, in the right order; analagous to the structure of DNA.

And I wanted to reach new audiences for the debate about genomics and encourage writers to look at this subject for inspiration. That’s why we teamed up with the Scottish Poetry Library to help publicise and judge the competition. I think we succeeded in this because the range of poems we received was huge. Writers from all over the world showed they weren’t afraid to tackle all sorts of areas such as cloning, stem cells, IVF... and clearly different countries are having debates about different aspects of the science. I think there’s a PhD project in examining how science reads across into other cultural activities in different countries.

There’s an indication in some of the entries we received that the most popular metaphor of DNA is perhaps too successful.



Steve Sturdy, Forum Deputy Director congratulates Sophie on her win.

Competition Winners

First Prize

Forward Deck by Sophie Cooke, Edinburgh

Second Prize

Digital by Nina Boyd, Yorkshire

Third Prize

Chromosome Medley

by Russell Jones, Edinburgh

Honourable mentions (in no order)

Improving the Human: “The Poet Gene”

by Scott Edward Anderson

Made by Katie Gooch

One of those by Ron Howland

Unchained melody of genes

by Ami Roseingrave

Improvements by Tony Williams

Enjoy all these poems by visiting: <http://bit.ly/hRY9tx>

It is growing harder to tell you apart,
in your superfine cruising clothes. genetically wondrous crew
shrink away from death Your perfections are various, yet
against one sunlit rail. You sing
on a merry motor yacht
that plots a straight and simple course.
Foxes fade to tales
your parents told;
the wind is dead, the great
Atlantic mirror
grows clearer every year
no waves disturb it, no breeze is needed.
And the decks of your hearts: stacked already in your favour. To be safe,
each plank can be replaced: a ship of aces.
No strangers call
at the doors of your bodies;
you have drained
chance from your bones.
You make yourselves new, in your own image,
catch it in brass and brilliant sunglasses.
Your sea has been resilvered.
Cell supplants cell
losing nothing
in the copy: an end
to age, to degradation. Time leaves no spots.
You lay your head against the sunrise, fresh as the only day that comes,
the day that is yesterday, tomorrow and today.
You sunbathe on the prow
while far below your wake
stays out of sight: you no longer
understand the word 'return'.
You have undone the wheel
and laid its arc out flat.
Only the muscle of manufacturers
turns over, dies beneath you
in the engine room: a bio-fuel
of brothers, forever being renewed.
You stand on the wasting shoulders
that pass in flashing turbines,
stand by the handrail and look
at the waveless mirror,
a horizon never reached:
reapply your perfection.

However seductive that idea might be to writers, DNA is not literally the letters A, C, G, and T. It is not a code, although we choose to read it as such. There's probably another PhD project in examining how scientific metaphors become so popular they are barely recognised as such, and get accepted as fact.

One of the implicit challenges in writing a poem 'about' something is judging how close or distant that poem should be to its inspiration. Many poems did not make it to the final shortlist because they were too obvious in the way they approached the theme and too insistent on their point of view. Conversely, several others were excellent poems, but the judges weren't able to spot how they had responded to the competition's specific challenge. We used Emily Dickinson's advice, 'tell all the truth but tell it slant' to guide us.

It also seemed that at least some level of ambivalence is essential for a good poem about science, and an ability to consider and illustrate all sides of the argument. Many poems did not make it to the final shortlist because they were too insistent that scientists play god. Equally, others were too optimistic about the possibilities of science. That may or may not be so. But, as ever, you need to show, not tell, in order to persuade your audience.

Our list of winners shows the variety in the subject matter, and also in style. A poem is nothing without a sense of style, and our winners were all hugely different, and yet all had this in spades. ■

Read the full judges report at: <http://bit.ly/hgCJj6>

Visit www.pippagoldschmidt.co.uk for more on her work with fiction and science

Genomics Poetry Competition: Reading Party

If you would like to meet some of our competition winners please join us at the Scottish Poetry Library on 13 April 2011 to celebrate poetry and science.

See network events p.24 for further details

Do poetry and science have much to say to each other?

In a Bright Ideas residency at the Genomics Forum, Tracey S. Rosenberg explored their connections from a variety of perspectives. Her work focused largely on the intersections between identity, formal poetry, and medical narrative – how can a sonnet, that classic 14-line structure, reflect the personal changes that arise through serious illness? Leading undergraduate workshops to explore these concepts, assisted by Forum writer-in-residence Ken MacLeod. During this fellowship period, Tracey was awarded a New Writers Award from the Scottish Book Trust for a proposed poetry manuscript to continue to develop these ideas.

Contact Tracey at: <http://tsrosenberg.wordpress.com/>

From poets to playwrights

The Forum is delighted to announce the launch of a new artistic venture.

In partnership with the Edinburgh Traverse Theatre an experienced Resident Playwright will be based within the Genomics Forum during 2011.

Continuing our success in engagements involving writers and artists with scientist and social researchers, we hope working alongside Forum members will inspire the creation of a genomics related play. Our ambition is to offer access to the creative process as the playwright works towards showcasing this new work in 2012.

For further information and to follow this residency visit: www.genomicsnetwork.ac.uk/forum



What drew you to working at Cesagen?

I was working at Sussex University as Senior Lecturer and the job advert was pointed out to me by a colleague. I was lucky that the role involved supervising the Cesagen Theme which covers many of my own areas of interest and research experience, resulting in a very good fit between myself and the role.

Have you always been interested in genomics?

I wrote about the impact of genetic testing on private health insurance for my Masters dissertation in 1994, so I have a longstanding interest in the social and ethical impact of developments in genetics. Technically, I've spent around 40% of my life interested in this topic – not 'always', but it sometimes feels like it.

What are you currently working on?

I am writing up a large ethnographic project on research ethics committees (completed before I moved to Cesagen) but am also interested in carrying out some work on inherited cardiac conditions (such as Long QT syndrome), looking at how different professional groups think about genetic testing for these conditions.

What have been your highlights of the last 12 months?

Aside from appearing on Radio 4's 'Thinking Allowed' with Laurie Taylor – the slow, steady progress I have been making in terms of thinking about my research ethics committee data. Now I just need to write it up – hopefully that'll be a highlight for 2011.

Who is your current work of interest to?

As well as the usual suspects – academics interested in bioethics, and research regulation – it links up with broader work in organisational sociology and is also of use to policy makers involved in running ethics review systems. This is a good time to be working in this area – the recent Academy of Medical Sciences review of biomedical research governance, and the Government's stated desire to create a single 'super-regulator' for research highlight the opportunities to engage with policy makers.

What is the most satisfying part of your job?

Writing. Reading Cesagen researchers' writing. Talking about writing – mine and other researchers'. Making my writing better. One current aim is to move outside the genomics 'ghettos', and speak to a broader range of sociological audiences. Work in the sociology of science has historically not been published in general interest sociology journals, yet our work speaks to central debates about modern societies and can illuminate discussions of stratification, work and identity.

What have been your key achievements?

Most recently it was becoming Associate Director of Cesagen. In terms of my overall career, I think getting my Wellcome Trust Postdoc (in 2000) was a crucial point. This research was the basis for my book, *The Politics of Personalised Medicine* which won a number of awards.

Where would you like to be in ten years' time?

I would like to be a sociologist of science, but in an environment where such work is seen as part of mainstream sociology, rather than a slightly marginal activity. I am lucky enough to be based in an institution that has a long history of work in science and technology studies and where sociology of science has been 'normalised' but I'm not sure how typical that is of departments elsewhere. ■

For further details on Adam Hedgecoe's work please visit: <http://bit.ly/eacnN8>

And for more information on Cesagen Research projects:
www.genomicsnetwork.ac.uk/cesagen

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To subscribe please contact: info@genomicsnetwork.ac.uk

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